Patient and spouse appraisals of health status in rheumatoid arthritis and fibromyalgia: discrepancies and associations with invalidation

M.B. Kool[1,3], H. Van Middendorp[2], J.W.J. Bijlsma[3], R. Geenen[1,3]

[1]Department of Clinical and Health Psychology, Utrecht University, Utrecht, The Netherlands; [2]Department Medical Psychology, Radboud University Nijmegen Medical Center, Nijmegen, The Netherlands; [3]Department of Rheumatology and Clinical Immunology, University Medical Center Utrecht, Utrecht, The Netherlands.

Marianne B. Kool, MSc
Henriët van Middendorp, PhD
Johannes W.J. Bijlsma, MD
Rinie Geenen, PhD

Please address correspondence and reprint requests to:
Marianne Kool, MSc,
Department of Clinical and Health Psychology,
Utrecht University, P.O. Box 80140,
3508 TC Utrecht, The Netherlands.
E-mail: m.b.kool@uu.nl

Received on December 6, 2010; accepted in revised form on July 8, 2011.

Clin Exp Rheumatol 2011; 29 (Suppl. 69): S63-S69.

Key words: rheumatoid arthritis, fibromyalgia, health status, spouses, social support, empathy

Funding: This study is supported by a grant from the Dutch Arthritis Association.

Competing interests: none declared.

ABSTRACT

Objectives. *The health problems of patients with rheumatoid arthritis and fibromyalgia are mostly invisible to others, which can lead to a discrepancy between patients' and spouses' appraisals of the severity of the health problems. As a consequence, some patients may feel 'invalidation' from their spouse, such as not being understood and believed. Aim of this study was to compare patients' and spouses' appraisals of the health status of patients with rheumatoid arthritis and patients with fibromyalgia, and to examine whether discrepancies in these appraisals are associated with invalidation experiences of the patient.*

Methods. *Eighty-four patients with rheumatoid arthritis and 95 patients with fibromyalgia filled out a health status questionnaire (MOS short-form general health survey, SF-20) and a questionnaire on invalidation by the spouse (Illness Invalidation Inventory, 3*I). The spouses appraised the patients' health status independently from the patients using a spouse version of the SF-20.*

Results. *Patients with fibromyalgia and their spouses appraised the patients' health status significantly worse than patients with rheumatoid arthritis and their spouses. The agreement between patients and spouses was generally fair with somewhat more agreement in rheumatoid arthritis than in fibromyalgia. Patient-spouse discrepancies in health status appraisals were not associated with invalidation experiences.*

Conclusions. *The invisibility of health problems in fibromyalgia and rheumatoid arthritis is not accompanied by large patient-spouse discrepancies of health status appraisals, which suggests that invalidation by spouses is not dependent on observable evidence such as clinical signs of damage or pathology.*

Introduction

Rheumatoid arthritis and fibromyalgia are disabling diseases in which symptoms like pain, fatigue, and stiffness lead to impaired functioning and participation in daily life. Health problems such as pain, stiffness, and reduced well-being and functioning of patients with rheumatoid arthritis and fibromyalgia are mostly invisible (1). This can lead to a discrepancy between patients' and spouses' appraisals of the severity of the health problems, which may explain why some patients experience invalidation from their spouse. Invalidation refers to cognitive, affective, and behavioral responses of others that are perceived as denying, lecturing, overprotecting, not supporting, and not acknowledging with respect to the condition of the patient (2).

According to social contract theory, observers look for observable evidence such as clinical signs of damage or pathology, because an individual is required to pay a cost (real pain) in order to be eligible to receive a benefit (help) (3). When this 'evidence' is missing, observers will be alert to the possibility of cheating (4), and they may underestimate patients' symptoms and deprive the patient from help. This could be experienced as invalidation by patients. In agreement with this theory, physicians tend to estimate patients' pain or functional disability as less severe than patients in case of an absence of medical evidence supporting the patients' pain or when the physician is primed to expect cheating (3, 5-8). Thus, based on social contract theory, discrepancies in health appraisals will occur when health problems are mostly invisible as in rheumatoid arthritis and fibromyalgia, and even more when there is a lack of physical deformity and objective laboratory findings as in fibromyalgia.

Considerations and observations suggest

that social contract theory may not hold for spouses of patients with rheumatoid arthritis or fibromyalgia. In contrast to distant observers such as medical professionals and external observers in experiments, spouses may appraise the severity of health problems differently, because the patient and spouse share daily life experiences, thoughts, and feelings, and because especially harmonious relationships will endure. Indeed, the presence or absence of medical evidence does not strongly influence judgments of the patients' pain intensity by people close to the patient (9), and spouses of patients may even overestimate patients' pain (10-17). Spousal overestimation may be as bad for the health status of the patient as spousal underestimation (12, 17), because both may be accompanied by inappropriate helping behaviour of the spouse or because overestimation of problems by the spouse is experienced by the patient as lecturing, disparaging, or overprotecting.

The aim of this study was to compare patients' and spouses' appraisals of the health status of patients with rheumatoid arthritis and patients with fibromyalgia and to examine whether discrepancies in these appraisals are associated with invalidation experiences of the patient. Since social contract theory does not appear to apply to spouses, we had no clear expectations regarding the extent of patient-spouse discrepancies in the patient groups. We did expect that a larger patient-spouse discrepancy, either underestimation or overestimation of the severity of health problems by the spouse, would be associated with invalidation experiences of patients (18). Insight into patient-spouse discrepancies and their role in invalidation may help in understanding and therapeutically targeting invalidation.

Materials and methods

Participants

Patients were recruited from the University Medical Center and the hospital Diakonessenhuis in Utrecht, The Netherlands. Participants were 84 patients with rheumatoid arthritis and 95 patients with fibromyalgia, and their spouses. Most couples were married or unmarried living together (96%); 4% had a steady relationship but lived separately. Inclusion criteria for patients were being 18 years or older and being diagnosed by a rheumatologist according to the American College of Rheumatology (ACR) criteria for rheumatoid arthritis (19) or fibromyalgia (20). Participants with both rheumatic conditions were excluded.

Patient groups were rather similar concerning most demographic characteristics (Table I). However, patients with rheumatoid arthritis were older (mean age: 56 *vs.* 52 years; *p*=0.001), more often retired (24% *vs.* 11%; *p*=0.02), included more men (21% *vs.* 5%; *p*=0.008), and were diagnosed a longer time ago (16 *vs.* 8 years; *p*<0.001) than patients with fibromyalgia. Parallel to the two patient groups, spouses of patients with rheumatoid arthritis and fibromyalgia differed with regard to age (mean age: 57 *vs.* 54 years; *p*=0.04) and gender (21% *vs.* 6% women; *p*=0.006). Spouses of patients with rheumatoid arthritis had less often a Workmen's Compensation Act/Benefit (4% *vs.* 13%; *p*=0.03), and were more often housewife or houseman (7% *vs.* 1%; *p*=0.04) than spouses of patients with fibromyalgia.

Procedure

The study was approved by the Medical Ethics Committee of the University Medical Center Utrecht. Eligible patients who were in files of the hospital received information letters by post and consent forms from their rheumatologist, one for themselves and one for their spouse. Patients and spouses who indicated interest to participate, independently received from the principal investigator a questionnaire booklet with return envelope and were asked to fill out the questionnaire booklet by themselves.

Of each condition, 425 patients (both patients with and without a spouse) were initially sent a letter by the rheumatologist with the request to participate in the study. The addresses form files included patients with fibromyalgia or rheumatoid arthritis who had visited the rheumatologist once. The patients were selected at random. The files were not up-to-date; some patients had died and others had been moved to an unknown address or foreign country. Participation was voluntary and researchers did not have addresses of the patients, 160 (38%) with rheumatoid arthritis and 201 (48%) with fibromyalgia answered that they wanted to receive questionnaires. Of the patients who received a questionnaire booklet, 142 (89%) with rheumatoid arthritis and 167 (83%) with fibromyalgia returned complete questionnaire booklets. Of those, 106 patients with rheumatoid arthritis and 123 patients with fibromyalgia had a spouse. Of these patients, 84 (79%) spouses of patients with rheumatoid arthritis and 95 (77%) spouses of patients with fibromyalgia participated in the study and sent back complete questionnaire booklets. There were no significant differences between the patients who did and who did not have a spouse who participated in the study with respect to the main variables of the study (health status and invalidation) or with respect to the demographic variables (education, work status, and co-morbidity). However, rheumatoid arthritis patients with a non-participating spouse were significantly older (67 *vs.* 56 years; *p*<0.001), more often retired (50% *vs.* 24%; *p*=0.03), and more often male (50% *vs.* 21%; *p*=0.01) than patients with a participating spouse. Fibromyalgia patients with a non-participating spouse had a significantly longer duration of symptoms (15.8 *vs.* 10.6 years; *p*=0.008) and were diagnosed a longer time ago (7.9 *vs.* 4.5 years; *p*=0.04) than patients with a participating spouse.

Instruments

Two questionnaire booklets were constructed, a patient and a spouse version. Both booklets included questions about demographic characteristics and patients' health status. The patient version also included questions about invalidation by the spouse.

The patients' experience of invalidation by the spouse was measured with the 8-item spouse scale of the 40-item (5 times 8 items) Illness Invalidation Inventory (3*I) (2). The 3*I assesses the extent of invalidation that patients experience by five different sources (spouse, family, medical profession-

Table I. Characteristics of patients with rheumatoid arthritis and patients with fibromyalgia and their spouses.

Characteristics	Rheumatoid arthritis		Fibromyalgia	
	Patient (n=84)	Spouse (n=84)	Patient (n=95)	Spouse (n=95)
Gender (female), n (%)**	66 (79%)	17 (21%)	90 (95%)	6 (6%)
Age (yrs), mean (SD)*	56.2 (11.1)	57.2 (11.6)	51.5 (12.1)	53.6 (11.7)
Marital status, n (%)				
Married / living together	81 (96%)		91 (96%)	
Living separately	3 (4%)		4 (4%)	
Education level, n (%)				
Primary	5 (6%)	1 (1%)	7 (7%)	5 (5%)
Secondary	52 (62%)	51 (61%)	71 (75%)	59 (62%)
Tertiary	26 (31%)	31 (37%)	17 (18%)	30 (32%)
Years with symptoms, mean (SD)	17.2 (11.5)	-	15.8 (11.8)	-
Years since diagnosis, mean (SD)*	15.6 (11.2)	-	7.9 (9.2)	-
Work status, n (%)				
Employed full-time	9 (11%)	36 (43%)	9 (10%)	53 (56%)
Employed part-time	15 (18%)	8 (10%)	28 (30%)	7 (7%)
Unemployed	4 (5%)	1 (1%)	9 (10%)	1 (1%)
Retired*	20 (24%)	30 (36%)	10 (11%)	24 (25%)
Workmen's Compensation Act/ Benefit*	22 (26%)	3 (4%)	22 (23%)	12 (13%)
Housewife*	3 (4%)	6 (7%)	21 (22%)	1 (1%)
Comorbidity, n (%)				
Rheumatic disease	-	1 (1%)	-	2 (2%)
Lung disease	4 (5%)	6 (7%)	10 (11%)	11 (12%)
Diabetes	7 (8%)	5 (6%)	9 (9%)	5 (5%)
Cancer	3 (4%)	6 (7%)	3 (3%)	3 (3%)
Cardiovascular disease	16 (19%)	13 (16%)	15 (16%)	19 (20%)
Psychiatric or psychological comorbidity*	2 (2%)	3 (3%)	9 (10%)	6 (6%)
Other diseases	20 (24%)	12 (14%)	34 (36%)	11 (12%)

Note. Significance of difference between the two groups as based on independent samples *t*-tests for continuous variables or χ^2-tests for categorical variables.*$p<0.05$, **$p<0.01$.

als, work environment, and social services). The spouse scale includes two factors: discounting (5 items representing more overt rejections of others, *e.g.*, "My spouse thinks I should be tougher") and lack of understanding (3 items representing more a lack of acknowledgment, *e.g.* the reverse score of "My spouse understands the consequences of my health problems or illness"). Participants indicated on a 5-point Likert-scale (1=*never*, 5=*very often*) how often during the past year they experienced the responses in the described way. Mean scores on discounting and lack of understanding were analysed. Higher scores represent more invalidation. Cronbach's α coefficients (a measure of internal consistency) of the discounting and lack of understanding factors were 0.78 and 0.69, respectively.

To measure health status, the MOS Short-Form General Health Survey (SF-20) patient (21) and spouse versions (items adjusted to appraisal of the patients' health by the spouse) were used. The SF-20 consists of 20 items, from which 4 subscales were derived: physical functioning (6 items, 2 response options), social functioning (1 item, 6 response options), mental well-being (5 items, 6 response options), and physical pain (1 item, 5 response options). Patients were asked to appraise their own health status, while spouses were asked to appraise the health status of the patient. Higher scores reflect better physical functioning, mental well-being, social functioning, and more severe pain. Cronbach's α coefficients of the physical functioning and mental-well-being scales were 0.74 and 0.88 for patients, and 0.73 and 0.88 for spouses, respectively.

Statistical analyses

SPSS 16.0 was used for data analyses with two sided significance ($p<0.05$). The score distribution of all variables was sufficiently normal and the sample size large enough to allow parametric statistics.

To take account of the dependence between scores of patients and spouses, their scores were analysed with repeated measures analyses of variance to examine whether different scores on health status were reported between patient groups (rheumatoid arthritis *vs.* fibromyalgia) and between patients *vs.* spouses. Differences between patients and spouses within each patient group were adjusted for age, gender, and psychological or psychiatric comorbidity differences between groups. The size of differences between patients and spouses was expressed in the effect size parameter partial eta-squared (η^2), with values of 0.01, 0.06, and 0.14 being considered small, moderate, and large, respectively (22).

Weighted Cohen's Kappa coefficient, a statistical measure for inter-rater agreement for ordinal data, was calculated to get insight into individual couple agreement regarding patients' health status. Weighted Cohen's Kappa takes into account the agreement expected by chance and the size of disagreement. Since mental well-being scores were measured on an interval scale, a weighted Cohen's Kappa coefficient was calculated using the rounded off scores of mental well-being. Cohen's Kappa is always less than or equal to 1; a kappa below 0.20 is considered to reflect poor agreement, a kappa between 0.20 and 0.40 fair agreement, a kappa between 0.40 and 0.60 moderate agreement, and a kappa greater than 0.60 good agreement (23).

The number and percentage of spouses who underestimate (the spouse scores the health better than the patient), overestimate (the spouse scores the health worse than the patient), and had an equal estimation of patients' pain and dysfunction were described for each patient group. Scores for physical and social functioning and mental well-being were reversed to physical and social dysfunction and lack of mental

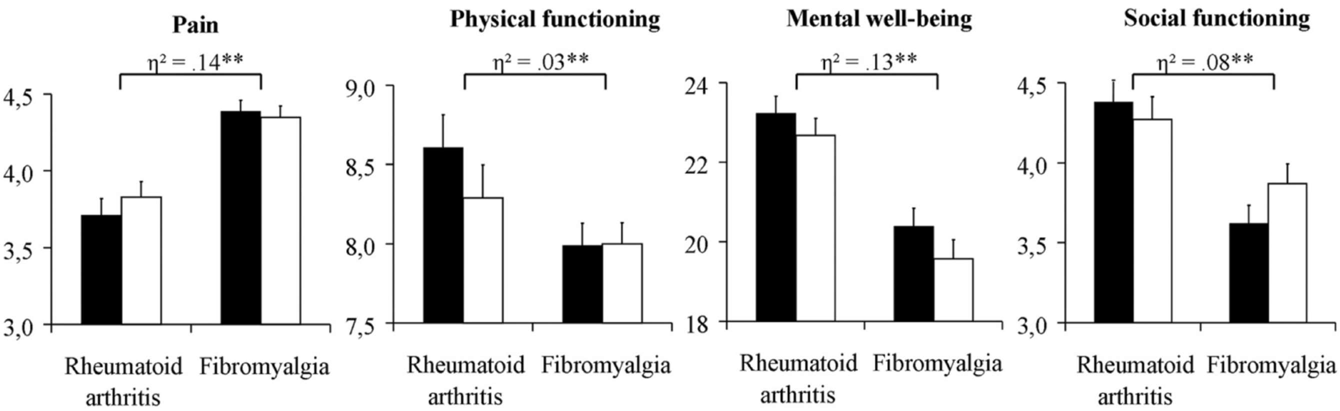

Fig. 1. Health status of patients with rheumatoid arthritis or fibromyalgia as perceived by patients (black bars) and spouses (white bars). η^2=partial eta-squared, represents the difference in patients' health status between the two patient groups (above the bars). $^*p<0.05$; $^{**}p<0.01$.

well-being to consistently interpret under- and overestimation in the same direction, as with patients' pain. The mean scores of discounting and lack of understanding of the spouses were calculated for patients with spouses who underestimate, overestimate, and estimate patients' health status equal. Analyses of variance and Bonferroni *post hoc* multiple comparisons were used to analyse differences in invalidation scores between the three groups (underestimation, equal estimation, and overestimation) for each aspect of health status separately, controlled for patient group (fibromyalgia *vs.* rheumatoid arthritis).

The power (1-beta) to detect a medium effect size of the main analyses was high for the "between group" comparison of patients with fibromyalgia and rheumatoid arthritis (0.97), the "within-group" comparison between patients and spouses (0.99), and the between-within interaction of patient group *patient and spouse report (0.99), and of the comparison between the numbers of underestimating, equal estimating and overestimating spouses (0.85); alpha=0.05, r=0.50, F=0.25 [G*Power 3: (24)].

Results

Patients and spouses appraisal of patients' health status

Patients with fibromyalgia as well as their spouses reported on average more severe pain, F(1.175)=28.52; $p<0.001$; $\eta^2=0.14$, a worse physical functioning, F(1.175)=4.44; $p=0.04$; $\eta^2=0.03$, a worse mental well-being, F(1.175)=26.44; $p<0.001$; $\eta^2=0.13$, and a worse social functioning, F(1.175)=14.33; $p<0.001$; $\eta^2=0.08$, than patients with rheumatoid arthritis as well as their spouses (Fig. 1).

In the total sample, spouses did not significantly appraise any aspect of patients' health status differently than patients ($p>0.05$). Analysis of interactions showed that patient-spouse discrepancies did not significantly differ in magnitude or direction between rheumatoid arthritis and fibromyalgia couples ($p>0.05$).

Patient-spouse agreement

The weighted Cohen's Kappa coefficients indicated moderate agreement between patients with rheumatoid arthritis and their spouses; physical functioning $\kappa=0.51$, pain $\kappa=0.43$, mental well-being $\kappa=0.44$, and social functioning $\kappa=0.52$. Patients with fibromyalgia and their spouses showed fair agreement with respect to physical functioning $\kappa=0.33$, pain $\kappa=0.35$, and social functioning $\kappa=0.36$, and moderate agreement with respect to mental well-being, $\kappa=0.50$.

Overall, in about 50% of couples, pa-

Table II. Number (percentages) of spouses that underestimate, estimate equal, and overestimate patients' health status scores (pain, physical dysfunction, lack of mental well-being, and social dysfunction).

Health status	Rheumatoid arthritis n. spouses (%)	Fibromyalgia n. spouses (%)
Pain		
Underestimation	15 (18%)	18 (19%)
Equal estimation	46 (55%)	61 (64%)
Overestimation	23 (27%)	16 (17%)
Physical dysfunction		
Underestimation	18 (21%)	29 (31%)
Equal estimation	32 (38%)	39 (42%)
Overestimation	34 (41%)	26 (27%)
Lack of mental well-being		
Underestimation	17 (20%)	14 (15%)
Equal estimation	47 (56%)	51 (54%)
Overestimation	20 (24%)	30 (31%)
Social dysfunction		
Underestimation	18 (22%)	34 (36%)
Equal estimation	40 (49%)	39 (41%)
Overestimation	24 (29%)	22 (23%)

Note. The percentages of the three groups (underestimation, similar, and overestimation) do not significantly differ between patients with fibromyalgia and patients with rheumatoid arthritis ($p>0.05$), on the basis of χ^2-tests for categorical variables.

tients and spouses had a similar appraisal of patients' health status (Table II). The number of spouses who underestimated or overestimated patients' health status did not differ to a large extent, with the exception that twice as many spouses of patients with rheumatoid arthritis overestimated (41%) than underestimated (21%) patients' physical dysfunction, and twice as many spouses of patients with fibromyalgia overestimated (31%) than underestimated (15%) patients' lack of mental well-being. Most spouses under- or overestimated patients' health status with 1 score. Disagreement scores were >1 for the following percentage of spouses of patients with rheumatoid arthritis and patients with fibromyalgia: lack of mental well-being 6% and 8%, pain 10% and 9%, social dysfunction 13% and 19%, and physical dysfunction 24% and 29%.

Spousal (dis)agreement and invalidation

Discounting and lack of understanding by the spouse did not significantly differ (*p*>0.05) between patients with spouses who underestimate, overestimate, and estimate patients' health status scores equal (Table III).

Table III. Mean scores (and standard deviations) of spouses' discounting and lack of understanding for three groups (spouse underestimation, spouse equal estimation, and spouse overestimatinon) with regard to 4 aspects of patients' health status (pain, physical dysfunction, lack of mental well-being, and social dysfunction) of patients with rheumatoid arthritis and patients with fibromyalgia combined, and F-value and *p*-value of the group differences (spouse underestimation, spouse equal estimation, and spouse overestimation).

	Discounting			Lack of understanding		
Health status	Mean (sd)	F	*p*	Mean (sd)	F	*p*
Pain		2.54	0.08		0.47	0.63
Underestimation	1.57 (0.64)			1.89 (0.71)		
Equal estimation	1.47 (0.47)			1.78 (0.72)		
Overestimation	1.67 (0.66)			1.86 (0.60)		
Physical dysfunction		0.44	0.65		1.05	0.35
Underestimation	1.58 (0.54)			1.88 (0.79)		
Equal estimation	1.50 (0.51)			1.71 (0.65)		
Overestimation	1.56 (0.62)			1.85 (0.62)		
Lack of mental well-being		0.69	0.50		0.72	0.49
Underestimation	1.62 (0.57)			1.94 (0.77)		
Equal estimation	1.52 (0.55)			1.79 (0.70)		
Overestimation	1.51 (0.53)			1.79 (0.63)		
Social dysfunction		1.49	0.23		0.41	0.67
Underestimation	1.67 (0.62)			1.89 (0.81)		
Equal estimation	1.48 (0.51)			1.77 (0.64)		
Overestimation	1.47 (0.53)			1.76 (0.64)		

Discussion

This study showed that spouses and patients appraise patients' health status in a rather similar way, although patients with rheumatoid arthritis and their spouses do agree somewhat more than patients with fibromyalgia and their spouses. On a group level, both patients and spouses appraise the health status of patients with fibromyalgia as worse than the health status of patients with rheumatoid arthritis. Neither underestimation nor overestimation of the severity of health problems by the spouse was associated with invalidation experiences of patients.

The finding that the patients with fibromyalgia report a worse health status than the patients with rheumatoid arthritis is consistent with earlier studies (25). However, it was as yet unknown that also the spouses of the two patient groups show the same difference in their appraisal of patients' health status. Although the credibility of patients with fibromyalgia is often called into question by others (26-29), our study indicates that spouses agree with patients that the health status is worse for fibromyalgia than for rheumatoid arthritis. The observation that spouses confirm the severity of the health status problems of patients with fibromyalgia underscores the necessity of developing and providing effective treatment for fibromyalgia.

The low discrepancy between patients and spouses regarding their appraisals of patients' health status is not in line with social contract theory (3) that would expect spouses to underestimate patients' symptoms because of the invisibility of the symptoms. The lack of medical evidence for fibromyalgia does not seem to lead to the underestimation of symptoms by spouses through suspicion or symptom uncertainty. Couples who share a life together may be considered to be able to appraise the subjective patients's health status. Likely, spouses will more often use affection, commitment, and other signs in their appraisal than more distant observers like family, colleagues, or physicians do (30). Moreover, patients may be more inclined to express their catastrophising thoughts to their spouse than to others (31, 32). Unlike previous studies, more spouses appraised patients' pain similar to patients than overestimating patients' pain (10-17). Measuring patients' health status with ordinal scales (5-level Likert items) instead of ratio scales (visual analogue scale of 100 mm) might have increased the chance of similar appraisals. Results of this study suggest that the invisibility of symptoms in rheumatoid arthritis and fibromyalgia does not hamper most spouses in estimating patients' health status similarly to patients.

Patient-spouse discrepancies in appraisals of the severity of health problems were hardly correlated with invalidation experiences of patients, in contrast to our hypothesis (18). Results of this study suggest that controversy regarding health between the patient and the spouse is not an important determinant of invalidation experiences of the patients. Experienced invalidation is perhaps due to other factors such as relationship satisfaction or different interpersonal expectations of patients and spouses (33). However, also the low prevalence of invalidation experiences and the low discrepancy between patients' and spouses' appraisals of patients' health status may have prevented the finding of an association. Invalidation from other less close potential sources of invalidation than the spouse, such as colleagues and employees working at social services, is generally higher than invalidation as experienced from the spouse (2). Obviously, the findings of the current study – and the disconfirmation of social contract theory – do not generalise to these other more distant sources. Research in other social sources than the spouse is important to explain invalidation experiences of patients.

The simultaneous inclusion of patients and spouses in this study, as well as the participation of two patient groups, made it possible to examine couple's appraisal of patients' health status and the difference between fibromyalgia and rheumatoid arthritis, which has not been studied before. The study was conducted in patients who voluntarily responded to an invitation of a rheumatologist to let researchers know that they were interested in receiving a questionnaire booklet. No reminders were sent to patients, because the researchers did not possess their addresses. Thus, the results do not generalise beyond patients who responded after having received a single information letter. Since invalidation scores did not differ between patients with participating and non-participating spouses, there is no indication that only patients with committed and acknowledging spouses participated. Although instructions were very clear, we cannot rule out the possibility that couples communicated during the filling out of the questionnaires or that spouses reported socially desirable answers. Furthermore, the use of self-reported measures, *e.g.* to assess psychiatric comorbidity, is a limitation. In future studies, the filling out of questionnaires in an experimental setting by patients and spouses separately could minimise one of these limitations.

Our study indicates that spouses do not question the credibility of the health problems of patients. Considering the severity of the health problems of patients with fibromyalgia and the lack of effective treatment, psychological help in learning patients to cope with the illness is important. Health appraisal discrepancies with other sources of invalidation, such as colleagues and social agencies, might play a role in invalidation experiences of patients with rheumatoid arthritis and patients with fibromyalgia, but patient-spouse discrepancies of health status appraisals are small, which suggests that invalidation by spouses is not dependent on observable evidence such as clinical signs of damage or pathology.

Acknowlegments

We are very grateful to the participants and to Paulien Vermaas and Miranda de Jong for their contribution to this project.

References

1. SPAETH M: Fibromyalgia – a challenge for health care systems or: Don't leave the physician out in the cold. *Clin Exp Rheumatol* 2010; 28: S1-2.
2. KOOL MB, VAN MIDDENDORP H, LUMLEY MA *et al*.: Lack of understanding in fibromyalgia and rheumatoid arthritis: the Illness Invalidation Inventory (3*I). *Ann Rheum Dis* 2010; 69: 1990-5.
3. KAPPESSER J, WILLIAMS AC, PRKACHIN KM: Testing two accounts of pain underestimation. *Pain* 2006; 124: 109-16.
4. COSMIDES L, TOOBY J: Evolutionary Psychology and the Generation of Culture .2. Case-Study - a Computational Theory of Social-Exchange. *Ethol Sociobiol* 1989; 10: 51-97.
5. POOLE GD, CRAIG KD: Judgments of genuine, suppressed, and faked facial expressions of pain. *J Pers Soc Psychol* 1992; 63: 797-805.
6. TAIT RC, CHIBNALL JT: Physician judgments of chronic pain patients. *Soc Sci Med* 1997; 45: 1199-205.
7. CHIBNALL JT, TAIT RC, ROSS LR: The effects of medical evidence and pain intensity on medical student judgments of chronic pain patients. *J Behav Med* 1997; 20: 257-71.
8. HIDDING A, VAN SANTEN M, DE KLERK E *et al*.: Comparison between self-report measures and clinical observations of functional disability in ankylosing spondylitis, rheumatoid arthritis and fibromyalgia. *J Rheumatol* 1994; 21: 818-23.
9. KAPPESSER J, DE C WILLIAMS AC: Pain judgements of patients' relatives: Examining the use of social contract theory as theoretical framework. *J Behav Med* 2008; 31: 309-17.
10. BEAUPRE P, KEEFE FJ, LESTER N, AFFLECK G, FREDRICKSON B, CALDWELL DS: A computer-assisted observational method for assessing spouses' ratings of osteoarthritis patients' pain. *Psychol Health Med* 1997; 2: 99-108.
11. CANO A, JOHANSEN AB, GEISSER M: Spousal congruence on disability, pain, and spouse responses to pain. *Pain* 2004; 109: 258-65.
12. CREMEANS-SMITH JK, STEPHENS MA, FRANKS MM, MARTIRE LM, DRULEY JA, WOJNO WC: Spouses' and physicians' perceptions of pain severity in older women with osteoarthritis: dyadic agreement and patients' well-being. *Pain* 2003; 106: 27-34.
13. KAPPESSER J, WILLIAMS AC: Pain estimation: Asking the right questions. *Pain* 2010; 148: 184-7.
14. MIASKOWSKI C, ZIMMER EF, BARRETT KM, DIBBLE SL, WALLHAGEN M: Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain* 1997; 72: 217-26.
15. MARTIRE LM, KEEFE FJ, SCHULZ R *et al*.: Older spouses' perceptions of partners' chronic arthritis pain: implications for spousal responses, support provision, and caregiving experiences. *Psychol Aging* 2006; 21: 222-30.
16. REDINBAUGH EM, BAUM A, DEMOSS C, FELLO M, ARNOLD R: Factors associated with the accuracy of family caregiver estimates of patient pain. *J Pain Symptom Manage* 2002; 23: 31-8.
17. RIEMSMA RP, TAAL E, RASKER JJ: Perceptions about perceived functional disabilities and pain of people with rheumatoid arthritis: differences between patients and their spouses and correlates with well-being. *Arthritis Care Res* 2000; 13: 255-61.
18. LEHMAN AJ, PRATT DD, DE LONGIS A *et al*.: Do Spouses Know How Much Fatigue, Pain, and Physical Limitation Their Partners With Rheumatoid Arthritis Experience? Implications for Social Support. *Arthritis Care Res* 2011; 63: 120-7.
19. ARNETT FC, EDWORTHY SM, BLOCH DA *et al*.: The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis Rheum* 1988; 31: 315-24.
20. WOLFE F, SMYTHE HA, YUNUS MB *et al*.: The American College of Rheumatology 1990 criteria for the classification of fibromyalgia. Report of the multicenter criteria committee. *Arthritis Rheum* 1990; 33: 160-72.
21. KEMPEN GIJM, BRILMAN EI, HEYINK JW, ORMEL J: Het meten van de algemene gezondheidstoestand met de MOS short-form general health survey (SF-20): een handleiding. (Measuring the general health status with the MOS short-form general health survey (SF-20): a manuel). Groningen: Noordelijk Centrum voor Gezondheidsvraagstukken, Rijksuniversiteit Groningen; 1995.
22. COHEN J: *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale: Lawrence Erlbaum Associates; 1988.
23. ALTMAN DG: *Practical Statistics for Medical Research*. London: Chapman & Hall; 1999.
24. FAUL F, ERDFELDER E, LANG A, BUCHNER A. G*POWER 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behav Res Methods* 2007; 39: 175-91.
25. HOFFMAN DL, DUKES EM: The health status burden of people with fibromyalgia: a review of studies that assessed health status with the SF-36 or the SF-12. *Int J Clin Pract* 2008; 62: 115-26.
26. CUNNINGHAM MM, JILLINGS C: Individuals' descriptions of living with fibromyalgia. *Clin Nurs Res* 2006; 15: 258-73.

27. HALLBERG LR, CARLSSON SG: Psychosocial vulnerability and maintaining forces related to fibromyalgia. In-depth interviews with twenty-two female patients. *Scand J Caring Sci* 1998; 12: 95-103.
28. KOOL MB, VAN MIDDENDORP H, BOEIJE H, GEENEN R: Understanding the lack of understanding. Invalidation from the perspective of the patient with fibromyalgia. *Arthritis Rheum* 2009; 61: 1650-6.
29. PAULSON M, DANIELSON E, SODERBERG S: Struggling for a tolerable existence: the meaning of men's lived experiences of living with pain of fibromyalgia type. *Qual Health Res* 2002; 12: 238-49.
30. SODERBERG S, STRAND M, HAAPALA M, LUNDMAN B: Living with a woman with fibromyalgia from the perspective of the husband. *J Adv Nurs* 2003; 42: 143-50.
31. CONVERSANO C, LENSI E, BAZZICHI L, SERNISSI F, DELL'OSSO L: How important are the psychological aspects in fibromyalgic syndrome? *Clin Exp Rheumatol* 2010; 28: S3-6.
32. EDWARDS RR, BINGHAM CO, BATHON J, HAYTHORNTHWAITE JA: Catastrophizing and pain in arthritis, fibromyalgia, and other rheumatic diseases. *Arthritis Rheum* 2006; 55: 325-32.
33. BEDIAKO SM, FRIEND R: Illness-specific and general perceptions of social relationships in adjustment to rheumatoid arthritis: The role of interpersonal ex pectations. *Annals Behav Med* 2004; 28: 203-10.