

Invalidation in Patients with Rheumatic Diseases: Clinical and Psychological Framework

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ABSTRACT. Objective. The term “invalidation” refers to the patients’ perception that their medical condition is not recognized by the social environment. Invalidation can be a major issue in patients’ lives, adding a significant burden to symptoms and limitations while increasing the risk of physical and psychological disability. In this study in patients with rheumatic diseases, we investigated the relationship between invalidation and sociodemographic, clinical, psychological, and personality characteristics.

Methods. This international cross-sectional study included 562 adults with rheumatoid arthritis (n = 124), spondyloarthritis (n = 85), systemic lupus erythematosus (n = 112), or fibromyalgia (FM; n = 241). Assessed were the family and health professionals subscales of the Illness Invalidation Inventory (3*I), happiness (Subjective Happiness Scale), personality (Ten-Item Personality Inventory), pain, and loneliness (numerical rating scales). Univariate and multivariate analyses were used to test different models.

Results. Invalidation occurred in all rheumatic diseases, but patients with FM reported the most invalidation. Including all correlated variables in the multivariate model, pain remained as a determinant of invalidation by health professionals, but not by family. Regarding psychological variables, loneliness remained as a determinant of invalidation by family, but not by health professionals. FM and low levels of happiness, agreeableness, and conscientiousness were associated with invalidation while taking account of other variables.

Conclusion. Invalidation occurs in all rheumatic diseases and patients with FM experience the most invalidation. Psychological factors (happiness, agreeableness, and conscientiousness), loneliness, and pain intensity are associated with invalidation, irrespective of the rheumatic disease and may deserve dedicated interventions. (First Release February 15 2017; J Rheumatol 2017;44:512–18; doi:10.3899/jrheum.160559)

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The term “invalidation” is used to describe the patients’ perception that their medical condition is not recognized by the social environment. It is a multifaceted phenomenon that includes nonacceptance, misunderstanding, disbelief, rejection, stigmatization, and suspicion that the problem is being exaggerated or has a purely psychological characteristic¹. Invalidation is a psychosocial phenomenon because it depends on the interaction between the provider, who may deliberately or unintentionally invalidate the patient, and the perceiver (the patient) and his or her personal interpretation

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of the emotional, behavioral, and cognitive responses provided by others¹.

Research on invalidation identified a hierarchical structure with 2 major dimensions: (1) lack of understanding and (2) discounting¹. Lack of understanding reflects a lack of positive responses such as not recognizing, not comprehending, and not emotionally supporting the patient. Discounting represents negative social responses and social rejection, including disbelieving, admonishing, dismissing inability to work, not acknowledging symptom fluctuations, and offering unusable advice². Lecturing and overprotecting are also identified by patients as forms of discounting¹, suggesting that even people who accept and support the patient may unintentionally trigger the experience of invalidation².

Positive social responses are important aids in coping with chronic diseases and they are thought to promote health and buffer the effect of external stressors on health³. Conversely, negative social responses (lack of support and understanding from others, invalidation) have a detrimental effect upon psychological well-being⁴ and seem to contribute to pain

amplification⁵, thus harming mental and physical health³. To avoid negative social responses, patients may isolate themselves from others, thus contributing to loneliness, depression, lack of self-esteem, and reduced physical activity^{5,6}. Therefore, invalidation can be a major issue in patients' lives, significantly adding to the overall burden of the disease⁷ and increasing the risk of physical and psychological disability⁸. This makes it important to understand this phenomenon and its contributing factors to develop and implement effective preventive and management strategies.

Some determinants of invalidation have been suggested by research. Higher levels of invalidation were found in patients with fibromyalgia (FM) than in those with more visible rheumatic conditions⁸. This was attributed to the absence of objective signs of disease that may legitimize pain, fatigue, and the related behavior in the eyes of others, although emotional and cognitive aspects of FM may also be involved. Invalidation has also been found to be associated with more severe loneliness in patients with rheumatic diseases⁹. Other factors related to invalidation (such as patient age, sex, marital status, and socioeconomic status) are relevant in this context because they may affect not only true invalidation by the social environment, but also the perception of invalidation by the patient⁸. Further, invalidation will likely also be related to personality characteristics that may act as resilience (e.g., agreeableness) or vulnerability factors for its perception (e.g., neuroticism). Happiness, a composite of life satisfaction, coping resources, and positive emotions, is considered a resilience factor against many forms of misery because it predicts desirable life outcomes in many domains¹⁰. It is hoped that understanding these complex interactions will assist in the development of management strategies to protect patients with rheumatic diseases from the experience of invalidation.

The aim of our study in patients with rheumatic diseases was to examine the relationship between invalidation and sociodemographic, clinical, psychological, and personality characteristics of patients in 2 social contexts that virtually every patient experiences: family, and health professionals.

MATERIALS AND METHODS

Patients and procedures. Our international cross-sectional study is part of an international online research project on invalidation in rheumatic diseases and was approved by the medical ethical review board of the University Medical Center Utrecht, the Netherlands (NL-16565.041.07 AvG/vb/07/13010). Participants were identified for an online questionnaire study in Dutch, English, French, German, Portuguese, or Spanish language. The personality questionnaires used in our current study were filled out only by respondents using the Portuguese language version of the questionnaire. Those participants were included only if they responded to all questions in Portuguese involving at least 1 of the relevant sources (family or health professionals) of invalidation.

Participants were invited through notices placed on the Websites of the Portuguese Associations of Patients with Rheumatic Diseases, media interventions, and by personal invitation at the Rheumatology Department of Centro Hospitalar e Universitário de Coimbra.

All the participants were 18 years or older and the diagnosis of rheumatic

disease was self-reported, on the condition that it had been established by a certified physician. Participants with 1 of the following rheumatic diseases were included: rheumatoid arthritis (RA), spondyloarthritis (SpA), systemic lupus erythematosus (SLE), and FM. To make comparisons between subgroups, patients having only 1 of these diagnoses were included. Participants who reported having more than 1 of these conditions or none of them were excluded from analyses.

Measurements and instruments. The online survey included questions about sociodemographic and clinical characteristics, such as age, sex, marital status, educational level, work status, and rheumatologic diagnosis. Participants also completed questionnaires assessing invalidation [the Illness Invalidation Inventory (3*I)]⁸, pain and loneliness (0 to 10 numeric rating scales), happiness (the Subjective Happiness Scale — Portuguese version)¹¹, and personality traits (the Ten-Item Personality Inventory)¹². Only the family and health professionals subscales of the 3*I were included in the analysis for our report because virtually all patients have experiences with these 2 potential sources of invalidation. For a description of these questionnaires and their psychometric properties, see the Supplementary Data (available with the online version of this article).

Statistical analysis. Categorical data are presented as numbers and percentages and continuous variables as means \pm SD. Differences between groups were assessed by independent samples Student t test and 1-way ANOVA with Bonferroni correction for multiple comparisons. Correlations between continuous variables were evaluated by Pearson correlation coefficient. The normal distribution of variables submitted to the above-mentioned parametric tests was confirmed by Kolmogorov-Smirnov test.

Multivariate regression analysis was performed to examine the relationship between invalidation (lack of understanding and discounting by family and by health professionals, as dependent variables) and all other variables identified as having a p value < 0.10 in univariate analysis. To avoid multicollinearity, independent variables with a variance influence factor higher than 10 were excluded. To examine the hypothesis that FM would be associated with invalidation outcomes, having FM was introduced as an independent variable to each of the 2 dependent invalidation variables by the family and health professionals (model series 1). In the model series 2, pain intensity was added to the variable used in model series 1. In model series 3, age, sex, and sociodemographic variables were introduced. In model series 4, psychological dimensions (loneliness, happiness, and personality traits) were added. This sequence of models was chosen to represent clinical practice, where variables that are immediately accessible would be considered first. The assessment of psychological variables requires specific tests not common in rheumatology practice and would be recommended only if they were shown to be relevant after considering the easily accessible variables. Only the variables that have statistically significant association with the dependent variables were included in the next series model. The "stepwise" method was used to enter the variables into the models. Adjusted R² was used to compare the models. P values < 0.05 were considered statistically significant. Data were analyzed using SPSS version 20.0 for Windows.

RESULTS

A total of 746 Portuguese residents responded to the Portuguese language survey. One hundred and eighty-four were excluded because they had either none (n = 143) or a combination of more than 1 of the selected diseases (RA, SpA, SLE, FM; n = 41). This study included the 562 remaining participants.

The demographic and clinical characteristics of the participants are presented in Table 1, which also shows the overall results of discounting and lack of understanding regarding the 2 sources analyzed in our report (for the complete results on the 5 possible sources of invalidation, see the

Table 1. Demographic features, clinical characteristics, and invalidation scores of the 562 participants. Pain and loneliness were assessed using a 0–10 numerical rating scale. Happiness and personality traits were assessed using composite scores, both varying from 1 to 7. Invalidation was assessed using the Illness Invalidation Inventory, varying from 1 to 5. In all cases, higher values represent higher levels of the correspondent characteristic. Values are mean \pm SD or n (%).

Characteristics	Values	
Age, yrs	41.4 \pm 11.7	
Female	482 (85.8)	
Marital status		
Single	156 (27.7)	
Married/partnered	357 (63.5)	
Divorced	43 (7.7)	
Widowed	6 (1.1)	
Education level, yrs		
\leq 4	12 (2.1)	
5–12	225 (40.0)	
$>$ 12	325 (57.9)	
Work status		
Employed	314 (55.9)	
Unemployed	212 (37.7)	
Retired	36 (6.4)	
Self-reported diagnosis		
RA	124 (22.1)	
SpA	85 (15.1)	
SLE	112 (19.9)	
FM	241 (42.9)	
Pain, 0–10	5.5 \pm 2.6	
Loneliness, 0–10	4.1 \pm 3.3	
Happiness, 1–7	4.4 \pm 1.5	
Personality traits, 1–7		
Extroversion	4.6 \pm 1.7	
Agreeableness	5.7 \pm 1.2	
Conscientiousness	5.8 \pm 1.2	
Emotional stability	3.2 \pm 1.5	
Openness	5.4 \pm 1.3	
Source of invalidation	Discounting	Lack of Understanding
Family	2.3 \pm 1.0	2.5 \pm 1.1
Health professionals	1.9 \pm 0.9	2.2 \pm 1.0

RA: rheumatoid arthritis; SpA: spondyloarthritis; SLE: systemic lupus erythematosus; FM: fibromyalgia.

Supplementary Data, available with the online version of this article). Overall, levels of discounting ($p = 0.001$) and lack of understanding ($p < 0.001$) were higher in relation to the family than to health professionals.

Discounting and lack of understanding by the family were higher for female patients ($t = 1.97$ and $t = 2.67$, respectively), those with secondary education (vs primary education; $F = 4.74$ and $F = 2.86$, respectively), and those unemployed or retired ($F = 5.78$ and $F = 4.03$, respectively), as represented in Table 2. Levels of invalidation by health professionals were not affected by these variables. ANOVA with correction for multiple comparisons showed that invalidation levels in patients with FM were significantly higher than levels in each of the other diagnoses ($p < 0.001$), for both discounting and lack of understanding from both the family and health profes-

sionals. Conversely, there were no significant differences between RA, SpA, and SLE. The variable “diagnosis” was recorded for further analysis as “FM versus not-FM”.

Table 3 presents the correlations between invalidation and continuous variables. Both the domains of invalidation from the 2 studied sources were significantly correlated with higher levels of pain and loneliness as well as lower levels of happiness, agreeableness, conscientiousness, emotional stability, and openness. All the correlations were weak to moderate in strength.

In multivariate regression analysis (Table 4), having FM explained about 10% of invalidation from family and about 5% from health professionals. Adding pain to the model explained an additional 1.5% to 2%. Adding the sociodemographic variables to the model explained an additional 1%, but almost all demographic variables were excluded in the model 4 series. Adding the psychological variables to the models resulted in the highest increment observed in all models, explaining an additional 10% in discounting from family, 12% in lack of understanding from family, 8% in discounting from health professionals, and 5.5% in lack of understanding from health professionals.

After including all variables in the model, FM remained a determinant of discounting and lack of understanding of both sources. Pain remained a determinant of invalidation from health professionals, but not from family. Regarding psychological variables, loneliness remained as a determinant of both discounting and lack of understanding from family, but not from health professionals. Low levels of happiness, agreeableness, and conscientiousness were associated with both domains of invalidation while taking account of other variables.

DISCUSSION

The aim of our study was to examine to what extent sociodemographic, clinical, psychological, and personality characteristics of patients with rheumatic diseases are associated with patients’ invalidation by the family and health professionals.

In line with previous studies, patients experienced more invalidation by family than by health professionals⁹. However, health professionals should be aware that some patients will also perceive invalidation by health professionals, which may impair the clinical encounter and its desired outcomes.

The most important correlations of invalidation are observed with FM, pain, loneliness, happiness, agreeableness, and conscientiousness. Moreover, we have confirmed that levels of invalidation were significantly higher among patients with FM when compared with RA, SpA, and SLE. This was expected given the absence of physical and laboratory evidence of disease in FM, thus promoting a discrepancy between the patient’s and the social environment’s judgments of the problem¹³.

Table 2. Mean invalidation scores (discounting and lack of understanding) according to categorical variables. Values are mean ± SD unless otherwise specified.

Categorical Variables	Discounting	Source: Family		Source: Health Professionals				
		p	Lack of Understanding	p	Discounting	p	Lack of Understanding	p
Sex								
Female	2.3 ± 1.0	0.05 ¹	2.5 ± 1.1	< 0.01 ¹	1.9 ± 0.9	0.98 ¹	2.2 ± 1.0	0.56 ¹
Male	2.1 ± 0.8		2.2 ± 0.9		1.9 ± 0.8		2.1 ± 0.9	
Marital status								
Single	1.8 ± 1.0	0.15 ²	2.0 ± 1.0	0.33 ²	1.0 ± 0.8	0.54 ²	1.0 ± 0.9	< 0.05 ²
Partnered	2.3 ± 1.0		2.5 ± 1.1		2.0 ± 0.9		2.2 ± 1.1	
Divorced	2.7 ± 1.1		2.7 ± 1.0		1.9 ± 0.8		2.2 ± 0.9	
Widowed	2.3 ± 1.1		2.2 ± 1.4		1.6 ± 0.5		1.2 ± 0.3	
Education								
Primary	1.7 ± 0.5	< 0.01 ^{2§}	1.9 ± 0.9	0.06 ²	1.5 ± 0.7	0.05 ²	2.0 ± 0.9	0.87 ²
Secondary	2.5 ± 1.0		2.5 ± 1.1		2.0 ± 0.9		2.1 ± 1.1	
Tertiary	2.3 ± 1.0		2.4 ± 1.1		1.9 ± 0.8		2.2 ± 1.0	
Work status								
Employed	2.2 ± 0.9	< 0.01 ^{2º}	2.4 ± 1.0	0.01 ^{2*}	1.9 ± 0.9	0.60 ²	2.2 ± 1.0	0.91 ²
Unemployed	2.5 ± 1.1		2.5 ± 1.1		2.0 ± 0.9		2.2 ± 1.0	
Retired	2.5 ± 1.0		2.8 ± 1.2		1.8 ± 0.7		2.2 ± 1.0	
Diagnosis								
RA	2.1 ± 0.9	< 0.001 ²	2.2 ± 1.0	< 0.001 ²	1.8 ± 0.8	< 0.001 ²	2.0 ± 1.0	< 0.001 ²
SpA	2.1 ± 0.8		2.2 ± 0.8		1.9 ± 0.8		2.0 ± 0.9	
SLE	2.1 ± 1.0		2.1 ± 1.0		1.7 ± 0.7		1.9 ± 0.9	
FM	2.7 ± 1.0		2.9 ± 1.1		2.2 ± 0.9		2.4 ± 1.1	

¹ P values were calculated by independent samples Student t test. ² P values were calculated by ANOVA with Bonferroni correction for multiple comparisons.

[§] Primary versus secondary (p = 0.03). ^º Employed versus unemployed (p < 0.01). ^{*} Employed versus retired (p = 0.04). RA: rheumatoid arthritis; SpA: spondyloarthritis; SLE: systemic lupus erythematosus; FM: fibromyalgia.

Table 3. Correlations between invalidation scores (discounting and lack of understanding) and continuous variables. P values were calculated by Pearson bivariate correlation.

Variables	Family				Health Professionals			
	Discounting		Lack of Understanding		Discounting		Lack of Understanding	
	Correlation Coefficient, r	p	Correlation Coefficient, r	p	Correlation Coefficient, r	p	Correlation Coefficient, r	p
Age	0.01	0.80	0.11	0.010	-0.04	0.32	0.03	0.45
Pain	0.28	< 0.001	0.27	< 0.001	0.24	< 0.001	0.22	< 0.001
Loneliness	0.34	< 0.001	0.37	< 0.001	0.15	< 0.001	0.16	< 0.001
Happiness	-0.25	< 0.001	-0.26	< 0.001	-0.24	< 0.001	-0.20	< 0.001
Extroversion	-0.03	0.53	-0.07	0.13	-0.09	0.04	-0.10	0.02
Agreeableness	-0.16	< 0.001	-0.20	< 0.001	-0.17	< 0.001	-0.17	< 0.001
Conscientiousness	-0.21	< 0.001	-0.17	< 0.001	-0.23	< 0.001	-0.17	< 0.001
Emotional stability	-0.20	< 0.001	-0.20	< 0.001	-0.14	0.001	-0.10	< 0.001
Openness	-0.07	0.088	-0.12	0.005	-0.11	0.01	-0.15	< 0.001

However, it must be stressed that invalidation is not a problem exclusive to patients with FM. It also affects patients with rheumatic conditions having visible signs of disease. In fact, lack of understanding from family members was reported to occur “sometimes” or “often” by 22%, 26%, and 24% of patients with RA, SpA, and SLE, respectively (see the online supplementary file, available with the online version of this article). Thus, although invalidation is mostly perceived by patients with FM, it is a problem and burden worthy of attention for patients with a diversity of rheumatic diseases.

Practicing clinicians may consider that the higher prevalence of invalidation in FM is related to a higher prevalence of psychological traits potentially associated with invalidation¹⁴. Our results indicate, however, that the relationship between FM and invalidation persists after inclusion of personality variables in the model. Moreover, pain intensity does not fully explain the higher level of invalidation in FM; pain persists as a determinant of invalidation after adjustment for FM diagnosis.

The relationship between pain and invalidation exists irrespective of the underlying disease. This indicates that

Table 4. Multivariable association between FM, pain, sociodemographic variables, psychological dimensions, and invalidation outcomes (discounting and lack of understanding) from family and health professionals. Models 1, 2, 3, and 4 refer to addition of independent variables: model 1 included FM as independent variable; in the model series 2, pain intensity was added; in model series 3, age and sex were introduced and also the sociodemographic variables that presented a $p < 0.01$ in univariate analysis; and in model series 4, psychological dimensions were added to the variables used in model series 3. Only the variable(s) that had statistically significant association(s) with the dependent variables were included in the next series model(s). Values are β .

Variables	Family								Health Professionals							
	Discounting Model				Lack of Understanding Model				Discounting Model				Lack of Understanding Model			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
FM	0.31 ^c	0.23 ^c	0.23 ^c	0.28 ^c	0.32 ^c	0.25 ^c	0.25 ^c	0.29 ^c	0.24 ^c	0.16 ^b	0.19 ^c	0.18 ^c	0.21 ^c	0.14 ^b	0.14 ^b	0.14 ^b
Pain	—	0.17 ^c	0.15 ^b	0.07	—	0.15 ^b	0.15 ^b	0.04	—	0.17 ^c	0.18 ^c	0.17 ^c	—	0.15 ^b	0.15 ^b	0.14 ^b
Age	—	—	-0.08	—	—	—	0.02	—	—	—	-0.13 ^b	-0.14 ^b	—	—	-0.04	—
Male ¹	—	—	0.01	—	—	—	-0.04	—	—	—	0.07	—	—	—	0.03	—
Marital status ²																
Married/partnered	—	—	—	—	—	—	—	—	—	—	—	—	—	—	0.04	—
Divorced	—	—	—	—	—	—	—	—	—	—	—	—	—	—	< 0.01	—
Widowed	—	—	—	—	—	—	—	—	—	—	—	—	—	—	-0.09	—
Educational level ³																
Secondary	—	—	0.05	—	—	—	0.03	—	—	—	0.05	—	—	—	—	—
Tertiary	—	—	-0.02	—	—	—	< 0.001	—	—	—	-0.04	—	—	—	—	—
Work status ⁴																
Unemployed	—	—	0.10 ^a	0.07	—	—	0.03	—	—	—	—	—	—	—	—	—
Retired	—	—	0.01	—	—	—	0.05	—	—	—	—	—	—	—	—	—
Loneliness	—	—	—	0.21 ^c	—	—	—	0.29 ^c	—	—	—	-0.07	—	—	—	-0.01
Happiness	—	—	—	-0.09 ^a	—	—	—	-0.08 ^a	—	—	—	-0.13 ^a	—	—	—	-0.10 ^a
Extroversion	—	—	—	—	—	—	—	—	—	—	—	-0.01	—	—	—	-0.04
Agreeableness	—	—	—	-0.08 ^a	—	—	—	-0.14 ^c	—	—	—	-0.10 ^a	—	—	—	-0.12 ^b
Conscientiousness	—	—	—	-0.15 ^c	—	—	—	-0.09 ^a	—	—	—	-0.18 ^c	—	—	—	-0.13 ^b
Emotional stability	—	—	—	< 0.01	—	—	—	0.01	—	—	—	0.04	—	—	—	-0.03
Openness	—	—	—	0.07	—	—	—	-0.02	—	—	—	< -0.01	—	—	—	-0.06
Adjusted R ²	0.09	0.11	0.12	0.22	0.10	0.12	0.12	0.24	0.06	0.08	0.09	0.17	0.04	0.06	0.06	0.12

¹ Reference: female. ² Reference: single. ³ Reference: primary. ⁴ Reference: employed. ^a $p < 0.05$. ^b $p < 0.01$. ^c $p < 0.001$. FM: fibromyalgia.

patients with higher pain scores tend to feel more frequently or strongly that people they interact with, including health professionals, do not respect their illness. This apparent overlap between physical pain and social pain¹⁵ may suggest that pain makes patients more vulnerable to invalidation, but it cannot be excluded that invalidation amplifies pain, or both.

Interestingly, pain is no longer significant in the family context after adjustment for the psychological variables. This may suggest that high individual levels of agreeableness, conscientiousness, and happiness may buffer the relationship between pain and invalidation within the family. However, pain is still part of the model for health professionals, after consideration of the psychological dimensions. Health professionals should take careful account of their interpretation of intense pain and feelings of invalidation in the clinical setting.

Regarding personality traits, emotional stability (the reverse of neuroticism) was associated with invalidation in univariate analysis, but not in multivariate analysis. This indicates that emotional stability or neuroticism is less relevant in experiencing invalidation when simultaneously considering other personality traits. Happiness persists as a significant counter to invalidation after adjustment for all the independent variables studies. Happiness is the tendency to experience life in a positive, satisfying way^{16,17,18}. It is

considered as a filter through which individuals read and experience life and its events that apparently acts as a buffer against invalidation.

Loneliness persists as an independent correlate of discounting and lack of understanding after adjustment for other factors, in the family context only. It has been reported that 30% to 50% of the patients with rheumatic diseases experience high levels of loneliness⁹. The relationship between loneliness and invalidation, whichever is cause and effect, may result in a downward spiral with potentially alarming consequences, such as increased mortality¹⁹.

None of the sociodemographic variables retain significant correlation with invalidation after adjustment for diagnosis, pain, and psychological domains, which is in agreement with previous studies⁸. The only exception is age: Younger patients tend to sense more discounting from health professionals. These observations should be taken into account when considering common preconceptions about invalidation: Women are not more prone than men to invalidation. Neither marital and employment status nor educational levels have a bearing upon invalidation. However, the skewed distribution of these variables may have obscured the correlations.

Our results should be seen in the context of the study's strengths and limitations. The cross-sectional design does not

allow us to draw any causal relationship between invalidation and the studied variables; it is conceivable that happiness or agreeableness, for instance, may operate as resilience factors against invalidation, but it is equally possible that invalidation will limit these psychological characteristics. Lonely people may be more suspicious of the intentions of others, but repeated invalidation may also foster loneliness.

The dimension and diverse characteristic of the sample, in age, sex, and sociodemographic and psychological features, is a positive aspect of our study. The diagnoses were self-reported. This may have affected the results, especially through the possible not reporting of the coexistence of FM with the other diagnoses. The prevalence and importance of this error cannot be ascertained. However, 22% of the total number of patients with RA in the original sample described concomitant FM, and were excluded from our analysis. This percentage is slightly higher than the frequencies reported by physicians, according to the literature, thus reducing the probability that a significant proportion of patients with RA in our included sample might have had concomitant FM²⁰. Besides, the correlations between the studied variables were low to moderate in strength, and our study was restricted to Portuguese-speaking patients — it is not possible to guarantee that these results can be extrapolated to other cultural settings.

Our results show that while considering themselves as potential sources of invalidation, health professionals should pay special attention to patients with FM, intense pain, and low levels of happiness, agreeableness, and conscientiousness. Younger patients have a greater tendency to feel discounting. The same patient profile is associated with a higher tendency to feel higher levels of invalidation in the family context; this tendency being increased by loneliness.

Such observations, and the recognition that invalidation might significantly reduce patients' quality of life, challenge the physician to a difficult exercise: to analyze these complex domains particularly in the patients who will be less prone to attract his empathy — patients who are by character less happy, kind, empathic, cooperative, compliant, self-controlled, and responsible. This risk becomes higher in the presence of FM. Family members might need education about rheumatic diseases and especially about FM to better understand the patient and the disease, and to change the attitudes and behaviors that convey invalidation. For patients, self-management support and interventions could aim at modifying maladaptive negative attributions about apparently invalidating actions of others and stimulating strategies that increase resilience such as acceptance and commitment therapy^{21,22}. Patients could also be trained on how to best cope with invalidation, including the acquisition of communication skills that would allow them to discuss their health more openly and rationally with others, and — if all other means fail — to help patients accept the situation. Health professionals would certainly benefit from increased

awareness and training on appropriate communication skills to avoid these feelings of invalidation and to improve other clinical outcomes^{23,24}.

ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

REFERENCES

1. Kool MB, van Middendorp H, Boeije HR, Geenen R. Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthritis Rheum* 2009;61:1650-6.
2. Kool MB, van de Schoot R, López-Chicheri García I, Mewes R, Da Silva JA, Vangronsveld K, et al. Measurement invariance of the Illness Invalidation Inventory (3*I) across language, rheumatic disease and gender. *Ann Rheum Dis* 2014;73:551-6.
3. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985;98:310-57.
4. Rook KS. The negative side of social interaction: impact on psychological well-being. *J Pers Soc Psychol* 1984;46:1097-108.
5. Eisenberger NI, Jarcho JM, Lieberman MD, Naliboff BD. An experimental study of shared sensitivity to physical pain and social rejection. *Pain* 2006;126:132-8.
6. Sgoifo A, Koolhaas J, Alleva E, Musso E, Parmigiani S. Social stress. Acute and long-term effects on physiology and behavior. *Physiol Behav* 2001;73:253-4.
7. Zangi HA, Hauge MI, Steen E, Finset A, Hagen KB. "I am not only a disease, I am so much more". Patients with rheumatic diseases' experiences of an emotion-focused group intervention. *Patient Educ Couns* 2011;85:419-24.
8. Kool MB, van Middendorp H, Lumley MA, Schenk Y, Jacobs JW, Bijlsma JW, et al. Lack of understanding in fibromyalgia and rheumatoid arthritis: the Illness Invalidation Inventory (3*I). *Ann Rheum Dis* 2010;69:1990-5.
9. Kool MB, Geenen R. Loneliness in patients with rheumatic diseases: the significance of invalidation and lack of social support. *J Psychol* 2012;146:229-41.
10. Cohn MA, Fredrickson BL, Brown SL, Mikels JA, Conway AM. Happiness unpacked: positive emotions increase life satisfaction by building resilience. *Emotion* 2009;9:361-8.
11. Spagnoli P, Caetano A, Silva A. Psychometric properties of a Portuguese version of the Subjective Happiness Scale. *Social Indicators Res* 2012;105:137-43.
12. Gosling SD, Rentfrow PJ, Swann WB Jr. A very brief measure of the Big-Five personality domains. *J Res Personality* 2003; 37:504-28.
13. Kool MB, van Middendorp H, Bijlsma JW, Geenen R. Patient and spouse appraisals of health status in rheumatoid arthritis and fibromyalgia: discrepancies and associations with invalidation. *Clin Exp Rheumatol* 2011;29 Suppl 69:S63-9.
14. Goldberg LR. The structure of phenotypic personality traits. *Am Psychol* 1993;48:26-34.
15. Eisenberger NI, Lieberman MD. Why rejection hurts: a common neural alarm system for physical and social pain. *Trends Cogn Sci* 2004;8:294-300.
16. Seligman ME, Csikszentmihalyi M. Positive psychology. An introduction. *Am Psychol* 2000;55:5-14.
17. Diener E, Oishi S, Lucas RE. Personality, culture, and subjective well-being: emotional and cognitive evaluations of life. *Annu Rev Psychol* 2003;54:403-25.
18. Tkach C, Lyubomirsky S. How do people pursue happiness?: relating personality, happiness-increasing strategies, and well-being. *J Happiness Stud* 2006;7:183-225.

19. Penninx BW, van Tilburg T, Kriegsman DM, Deeg DJ, Boeke AJ, van Eijk JT. Effects of social support and personal coping resources on mortality in older age: the Longitudinal Aging Study Amsterdam. *Am J Epidemiol* 1997;146:510-9.
20. Yunus MB. The prevalence of fibromyalgia in other chronic pain conditions. *Pain Res Treat* 2012;2012:584573.
21. Hawkey LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. *Ann Behav Med* 2010;40:218-27.
22. Hayes SC, Strosahl KD, Wilson KG. Acceptance and commitment therapy. New York: Guilford Press; 2003.
23. Butow P, Sharpe L. The impact of communication on adherence in pain management. *Pain* 2013;154 Suppl 1:S101-7.
24. Kenny DT. Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm. *Patient Educ Couns* 2004;52:297-305.