

ONLINE SUPPLEMENTARY DATA

Invalidation

Invalidation was measured with the Illness Invalidation Inventory (3*I), which includes eight questions to assess discounting (5 items) and lack of understanding (3 items), though a 1 to 5 numerical rating scale (never to very often). The same question set is applied to assess five different sources: spouse, family, health professionals, work environment and social services. Participants indicated how often during the past year people within each category responded to them in the described way. The 3*I is a self-report questionnaire which has been shown to have adequate internal consistency and validity for each source in patients with rheumatic diseases from several countries including Portugal. Cronbach's α coefficients of the factor discounting were high, from 0.80 (spouse) to 0.94 (social services). Four Cronbach's α coefficients of the factor lack of understanding were high, from 0.79 (work environment) to 0.93 (social services), and one was moderately high, 0.67 (spouse).[1] The 3*I showed measurement invariance across gender, rheumatic disease and language, which shows that it is appropriate to compare and pool scores of the 3*I across groups. [2] We elected to analyze the data related to family and health professionals as sources of invalidation.

Pain and Loneliness

Zero to 10 numeric rating scales were used to measure pain and loneliness. Participants were asked to quantify their pain through the following question: "*How would you describe the overall level of pain you experienced during the past week?*" and loneliness through answering the question: *How would you describe the overall level of loneliness you experienced during the past week?* The one-item Likert-type scale has been shown to be an adequate way to measure a construct and useful when time or questionnaire space is limited. [3, 4]

Happiness

Happiness was measured by the Subjective Happiness Scale (Portuguese version). This scale consists of 4 items using a 7-point Likert scale, the average being taken as the Happiness score (range 1 to 7). Two items ask respondents to characterize themselves using both absolute ratings and ratings relative to peers, whereas the other two items offer brief descriptions of happy and unhappy individuals and ask respondents the extent to which each characterization describes them. The subjective Happiness Scale is a validated instrument with high internal consistency and stability across different population samples. The investigation psychometric properties of the Portuguese version have been studied and demonstrated high reliability ($0.73 > \text{Cronbach's } \alpha < 0.80$). [5]

Personality traits

We examined the Big-Five personality dimensions using the Ten-Item Personality Inventory (TIPI), [6] which was designed to assess the basic personality dimensions defined by the Five Factor Theory of Personality: Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Openness to Experience. The questions begin with the sentence "I see myself as...", and a score from 1 to 7 is requested to each question. Each dimension is represented by the average score of the respective two questions, with higher scores indicating a closer identification with that trait. TIPI was designed to measure very broad domains with only two items per dimension and using items at both the positive and negative poles. With only two items to reflect the broad dimension of the big 5 factor, TIPI is a scale in which validity exceeds reliability. It is an appropriate and often used instrument with adequate levels of validity, test-retest reliability and external correlates. [6]

REFERENCES

- 1 Kool MB, van Middendorp H, Lumley MA, *et al*. Lack of understanding in fibromyalgia and rheumatoid arthritis: the Illness Invalidation Inventory (3*1). *Ann Rheum Dis* 2010;69:1990-5.
- 2 Kool MB, van de Schoot R, Lopez-Chicheri Garcia I, *et al*. Measurement invariance of the Illness Invalidation Inventory (3*1) across language, rheumatic disease and gender. *Ann Rheum Dis* 2014;73:551-6.
- 3 Davey HM, Barratt AL, Butow PN, *et al*. A one-item question with a Likert or Visual Analog Scale adequately measured current anxiety. *J Clin Epidemiol* 2007;60:356-60.
- 4 Temel JS, Pirl WF, Recklitis CJ, *et al*. Feasibility and validity of a one-item fatigue screen in a thoracic oncology clinic. *J Thorac Oncol* 2006;1:454-9.
- 5 Spagnoli P, Caetano A, Silva A. Psychometric Properties of a Portuguese Version of the Subjective Happiness Scale. *Social Indicators Research* 2012;105:137-43.
- 6 Gosling SD, Rentfrow PJ, Swann Jr WB. A very brief measure of the Big-Five personality domains. *Journal of Research in Personality* 2003;37:504-28.

Online Supplementary Tables

Supplementary Table 1. Invalidation scores of the 562 participants, regarding the five possible sources.

Source of invalidation	<u>Discounting</u>	<u>Lack of Understanding</u>
Spouse	2.1 ± 0.9	2.2 ± 1.1
Family	2.3 ± 1.0	2.5 ± 1.1
Health Professionals	1.9 ± 0.9	2.2 ± 1.0
Work environment	2.6 ± 1.1	3.1 ± 1.1
Social Service	2.5 ± 1.1	3.1 ± 1.2

Supplementary Table 2. Number and frequency of patients perceiving invalidation “sometimes” or “often” according to diagnosis.

		FM (n=241)		RA (n=124)		SpA (n=85)		SLE (n=112)	
		n	%	n	%	n	%	n	%
Family	Discounting	110	45.6	23	18.5	17	20.0	24	21.4
	Lack of understanding	127	52.7	27	21.8	22	25.9	27	24.1
Health professionals	Discounting	52	21.6	11	8.9	12	14.1	7	6.3
	Lack of understanding	93	38.6	26	21.0	15	17.6	12	10.7

Abbreviations: FM, fibromyalgia; RA, rheumatoid arthritis; SpA, spondyloarthropathies; SLE, systemic lupus erythematosus.

A mean score ≥ 3 was taken as cut-off criterion (1=never, 2=seldom, 3=sometimes, 4=often, 5=very often).