Embitterment in patients with a rheumatic disease after a disability pension examination: occurrence and potential determinants

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Abstract

Objective

Health care and vocational professionals regularly encounter patients with rheumatic diseases who are embittered after a disability pension examination. People who are embittered typically feel victimised, experience resentment and injustice, resist help, and have difficulty coping. Our objective was to examine the occurrence of embitterment in patients with rheumatic diseases after a disability pension examination and the association of embitterment with its possible determinants helplessness and illness invalidation at work.

Methods

*The Illness Cognition Questionnaire (ICQ), Illness Invalidation Inventory (3*I), and Bern Embitterment Inventory were completed by patients who had 9 to 12 weeks earlier received the result of a disability pension examination. Diagnoses were fibromyalgia (n=103), rheumatoid arthritis (n=46), osteoarthritis (n=158), another rheumatic disease (n=62), and more than one rheumatic disease (n=187). Scores were compared to scores of reference groups. Hierarchical regression analyses were conducted.*

Results

Eighteen to 27 percent of patients had high levels of embitterment with no differences between diagnostic groups ($p=0.71$). Helplessness ($p<0.001$), the two invalidation dimensions discounting and lack of understanding ($p<0.001$), and the combination of helplessness with these invalidation dimensions ($p<0.01$), were predictive of more embitterment.

Conclusion

Our results suggest that, after a disability pension examination, embitterment is present in about one out of five patients with a rheumatic disease. This is problematic insofar as embitterment limits well-being, functioning, and the potential to reintegrate to work. To the extent that helplessness and invalidation at work are causal determinants of embitterment, interventions targeting these aspects may be key to reduce embitterment.

Key words

musculoskeletal diseases, sick leave, workers' compensation, helplessness, social support, hostility

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Introduction

Symptoms and musculoskeletal problems limit the ability of patients with a rheumatic disease to work. In many countries, patients with a rheumatic disease apply for disability pension after a mandatory period of vocational rehabilitation efforts. Both disability and the disability pension examination go with low levels of well-being (1, 2). Some patients turn embittered; they perceive injustice and resentment with regard to their situation, view themselves a victim of external causes, and resist moving ahead or accepting help to improve their situation (3, 4). Health care and vocational professionals regularly encounter patients with rheumatic diseases who are embittered after a disability pension examination. Research of embitterment in the context of disability is urgently needed (5). Up to now, the occurrence of embitterment in patients with rheumatic diseases who apply for a disability pension is unknown.

To prevent embitterment and to help people deal with it, it is important to know what factors contribute to the development or persistence of this disabling condition. Two possible determinants are examined in this article, invalidation and helplessness. Invalidation refers to responses of others that are judged to be denying, lecturing, not supporting, and not acknowledging the person's condition (6). Perhaps due to the invisibility of the primary symptoms pain, fatigue, and reduced musculoskeletal function that hamper work ability, patients with rheumatic diseases regularly face invalidation by colleagues and superiors at work (6). As observed by clinical experts (7) and in our previous study in patients with a rheumatic disease (8), we expect that invalidation at work will also be associated with embitterment in the current sample of patients after a disability examination. Another individual difference variable that will be related to embitterment is helplessness (3, 4). The progressive, fluctuating, and often unpredictable disease course may make patients with rheumatic diseases particularly vulnerable to become helpless (9, 10). Helpless patients will be more prone to embitterment, because they are incapable of mastering their aversive situation. As helpless people are also less able to deal with invalidation, we predict that especially those helpless individuals who perceive invalidation at work will be more prone to embitterment.

The aim of the present study in patients with rheumatic disease after a disability pension examination was to examine the occurrence of embitterment and the association of embitterment with helplessness and two aspects of invalidation at work, discounting (*i.e.* negative social responses and rejection) and lack of understanding (*i.e.* a lack of positive social responses and support). Embitterment was hypothesised to be higher in patients after a disability pension examination than in reference groups (general population and employed patients with a rheumatic disease). Moreover, embitterment was hypothesised to be high when helplessness, invalidation and especially their combination was high.

Materials and methods

Patients and procedure

Patients who had recently (9 to 12 weeks) received the result of their disability pension examination were invited to participate. From March to October 2010, the Dutch Workers Insurance Authority [Uitvoeringsinstituut Werknemersverzekeringen (UWV)] had sent letters to patients to inform them of the study, with an enclosed information letter of the researchers. Patients who were willing to participate returned an informed consent form to the researchers. The study was conducted according to the principles of the Declaration of Helsinki (6th revision, Seoul, 2008).

Reference groups of working patients not having a disability pension examination as derived from our previous study (8) included 64 patients with fibromyalgia (94% female; average age 45.0±11.3 years) and 32 patients with rheumatoid arthritis (81% female; average age 47.7±10.8 years). The population reference group included 159 research participants from the general population (47% female, average age 33.4±16.7 years) (11).

All patients filled out questionnaires assessing embitterment and helplessness. Invalidation was assessed in patients

who had been employed during the past year.

Instruments

Embitterment was measured using the Bern Embitterment Inventory (12). Participants rated their agreement with 18 statements on a 5-point scale ranging from 0 (does not apply) to 4 (fully applies). The general factor embitterment comprises four correlated subscales: emotional embitterment, performance-related embitterment, pessimism/hopelessness, and misanthropy/aggression (4). Two scores were provided: a continuous score and a count score indicating the amount of patients having embitterment levels (*i.e.* above 2.2) that may qualify for therapeutic attention (13). In the current study, internal consistency of the general embitterment scale was good: Cronbach's α=0.92.

Helplessness was measured using the Helplessness scale of the Illness Cognition Questionnaire (ICQ) (9). Helplessness was measured with six items; *e.g.* 'My illness frequently makes me feel helpless' and 'My illness controls my life' rated on 4-point scales from 1 (not at all) to 4 (completely). Internal consistency for helplessness in our study was good: Cronbach's α=0.84.

Invalidation by the work environment was assessed using the Illness Invalidation Inventory (3*I) (6). This inventory includes five items assessing discounting (*e.g.* 'people at work make me feel like an exaggerator') and three items with reversed scores assessing lack of understanding (*e.g.* 'people at work understand the consequences of my health problems or illness'). Participants indicated on a 5-point scale ranging from 1 (never) to 5 (very often) how often during the past year people in their work environment reacted to them in the described way. In the current study, Cronbach's α for discounting (α=0.90) and lack of understanding (α=0.86) were good.

Statistical analysis

The analyses were performed with SPSS for Windows 16.0. Significance level was set at $p<0.05$ (2-tailed). Continuous variables were expressed as mean ± standard deviation [SD] and discrete variables were presented as percentages. The distribution of the continuous variables was normal as indicated by absolute skewness and kurtosis values being below 1.

Differences between group characteristics were examined using the independent samples *t*-test and analysis of variance for continuous variables and Chi2-test test for discrete variables. Covariates associated with embitterment were selected using $p<0.10$ as a criterion for the Pearson *r* correlation coefficient for the continuous variable age and independent samples *t*-tests and analysis of variance for the discrete variables gender, marital status, education level, work status and the outcome of the disability pension examination.

To test the hypothesis that patients after the disability pension examination have higher embitterment than reference groups, analyses of covariance were applied while controlling for the selected covariates. The hypothesis that helplessness, illness invalidation, and their combination predict embitterment was tested with hierarchical regression analyses. These analyses included the patients who had been employed during the past year. Covariates were entered in block 1. After centering of the helplessness and invalidation variables (14), in block 2, helplessness and invalidation were entered, and in block 3, the helplessness × invalidation interaction. To interpret significant interactions, simple slopes analyses were performed and regression lines for individuals with low (-1 SD) and high (+1 SD) levels of invalidation were plotted for low (-1 SD) and high (+1 SD) levels of helplessness (15). The magnitude of differences was indicated with Cohen's d effect sizes with values of 0.20, 0.50, and 0.80 representing small, medium, and large effects, respectively (16).

Results

Patient characteristics

Of 2,184 patients who were contacted, 561 (26%) returned the informed consent form. Five patient groups were constructed on the basis of self-reported diagnoses: fibromyalgia (FM), rheumatoid arthritis (RA), osteoarthritis (OA), another rheumatic disease, and more than one rheumatic disease. Ankylosing spondylitis (n=17) and psoriatic arthritis (n=11) were the most prevalent diseases in the 'other' group. The diagnosis of 5 patients was unknown.

Patient characteristics are shown in Table I. Patient groups differed with respect to gender, age, education level, and the outcome of the disability examination (all $p<0.001$). With regard to the disability examination, patients with fibromyalgia were more often judged "not disabled" (<35% disabled) than patients with rheumatoid arthritis (χ^2=9.25, df=1, p=0.002) and more often judged "not disabled" (χ^2=6.66, df=1, p=.01) and less often judged "fully disabled" (80–100% disabled) (χ^2=7.07, df=1, p=0.008) than patients with another rheumatic disease and patients with more than one rheumatic disease (χ^2=13.97, *df*=1, $p<0.001$) (χ^2=18.09, df=1, $p<0.001$)). Patients with osteoarthritis were more often judged "not disabled" than patients with rheumatoid arthritis (χ^2=6.09, df=1, p=0.014) and more often judged "not disabled" (χ^2=12.12, df=1, $p<0.001$) and less often judged "fully disabled" (χ^2=15.48, df=1, $p<0.001$) than patients with more than one rheumatic disease.

The current patients with rheumatoid arthritis did not significantly differ from working patients with rheumatoid arthritis not having a disability pension examination with regard to gender (p=0.06), age (p=0.91), marital status (p=0.11), and education level (p=0.18). The current patients with fibromyalgia did not differ from and working patients with fibromyalgia not having a disability pension examination with regard to gender (p=0.91), age (p=0.07), and marital status (all p=0.10), but groups did differ with regard to education level (χ^2 = 22.41, df = 2, $p<0.001$), with the current group more often having a medium and less often a high education level.

Covariates of embitterment

Embitterment in men (1.59±0.93) was almost significantly higher than embitterment women (1.44±0.83) (t=1.88, p=0.06). Being younger (r=-0.14, p=0.001, n=550), unpartnered *versus* partnered (t=2.59, p=0.01), and unemployed *versus* part-time employed

Table I. Characteristics of patients with fibromyalgia (FM), rheumatoid arthritis (RA), osteoarthritis (OA), patients with a single diagnosis of another rheumatic disease, and patients with more than one rheumatic diagnosis (multiple).

	FM (n=103)	RA (n=46)	OA (n=158)	Other (n=62)	Multiple (n=187)
Female gender, n (%)*	97 (94)	28 (61)	91 (58)	41 (66)	148 (79)
Age (years), mean (SD)¥	42.0 (9.4)	47.4 (10.1)	53.9 (6.7)	47.3 (10.5)	50.7 (8.8)
Marital status, n (%)					
Single	10 (10)	8 (17)	17 (11)	7 (11)	24 (13)
Married/partnered	84 (82)	32 (70)	126 (80)	51 (82)	144 (77)
Divorced	9 (9)	5 (11)	13 (8)	3 (5)	14 (8)
Widowed	0	1 (2)	2 (1)	1 (2)	3 (2)
Education level, n (%)					
Low	3 (3)	1 (2)	17 (11)	5 (8)	12 (7)
Medium	95 (93)	34 (74)	132 (84)	47 (77)	148 (80)
High	4 (4)	11 (24)	8 (5)	9 (15)	24 (13)
Work status, n (%)					
Employed full time	0 (0)	1 (2)	14 (9)	2 (3)	3 (2)
Employed part time	25 (24)	20 (44)	28 (18)	16 (26)	43 (23)
Unemployed	78 (76)	25 (54)	111 (73)	44 (71)	139 (75)
Disability examination outcome, percentage (classification)‖§					
80-100% (fully disabled)	27 (26)	19 (41)	54 (34)	29 (47)	104 (56)
35-79% (partly disabled)	21 (21)	15 (33)	30 (19)	13 (21)	30 (16)
<35% (hardly disabled)	54 (53)	12 (26)	73 (46)	20 (32)	53 (28)

Education level. Low: primary education; Medium: lower and secondary vocational education, general secondary education; High: higher vocational education and academic education.
*χ^2 (4,555) = 49.91, p<0.001; ¥ F (4,541) = 30.70, p<0.001; §χ^2 (8, 550) = 28.81, p=0.001; ‖χ^2 (8, 554) = 37.58, p<0.001.

Table II. Embitterment (scale range 0–4) in five groups of patients with rheumatic diseases after a disability pension examination (left) and two reference groups of working patients (right).

	Patients after a disability pension examination					Working reference patients	
Variables	FM (n=103)	RA (n=46)	OA (n=158)	Other (n=62)	Multiple (n=187)	FM (n=64)	RA (n=32)
Embitterment							
Mean	1.67	1.54	1.41	1.44	1.45	1.25	0.80
SD							
High embitterment	0.85	0.96	0.80	0.90	0.88	0.86	0.69
n	28	12	28	13	36	10	1
%	27	26	18	21	19	16	3
Helplessness							
Mean	16.05	14.85	15.29	15.11	15.39	12.05	10.19
SD	3.34	3.43	4.28	3.55	3.99	3.89	3.18
Invalidation: discounting							
Mean	2.74	2.03	2.12	2.48	2.47	2.43	1.80
SD	1.05	0.75	0.89	1.00	1.12	0.91	0.71
Invalidation: lack of understanding							
Mean	3.04	2.58	2.71	3.01	2.98	2.86	2.47
SD	1.00	0.77	1.07	0.92	1.02	0.79	0.72

FM: fibromyalgia; RA: rheumatoid arthritis; OA: osteoarthritis; Other. another rheumatic disease; Multiple: having more than one rheumatic disease.
High embitterment indicates the number of patients above the cut-point of 2.2 (10).

(t=3.67, p<0.001) were associated with more embitterment. Education level (p=0.47) and the outcome of the disability pension examination were not associated with embitterment (p=0.47).

Comparison of group embitterment scores

The top of Table II shows the embitterment scores in the groups of patients. Analysis of covariance comparing embitterment in the groups of patients while adjusting for gender, age, marital status [single or partnered] and work status [unemployed or part-time employed] showed no difference in embitterment (F=0.72, p=0.58).

High embitterment was reported by 18% (osteoarthritis) to 27% (fibromyalgia) of the patients after the disability examination. In a sample from the Dutch general population (11), 3% experienced levels of embitterment above the cut-off value of 2.2.

In analysis of covariance while adjusting for gender, age, marital status [single and partnered] and education level [medium and high] , both the patients with fibromyalgia (F=6.61, p=0.01) and the patients with rheumatoid arthritis (F=6.90, p=0.01) after the disability pension examination had a higher level of embitterment than the working patients of the reference group (8).

Helplessness and illness invalidation predicting embitterment

Table III shows the results of the regression analyses with the covariates, helplessness, and the invalidation dimensions predicting embitterment. This analysis included the 313 participants who had been employed during the past year; due to missing values a final number of 299 patients were included in analyses. The level of embitterment for this group (1.36±0.85) was lower than for the group not being employed (1.63±0.85) (t=3.72, p<0.001). In Block 1, male gender (t=-2.21, p=0.03), being younger (t=-2.07, p=0.04), and not having a partner (t=-1.98, p=0.048) predicted more embitterment. In Block 2, embitterment was additively predicted by more discounting (t=6.12, p<0.001) and helplessness (t=7.82, p<0.001), and by more lack of understanding (t=5.52, p<0.001) and helplessness (t=8.53, p<0.001). In block 3, both the interaction between helplessness and discounting (t=2.76, p=0.01) and the interaction between helplessness and lack of understanding (t=2.81, p=0.005) predicted more embitterment. Figure I shows these interactions. Most pronounced were the high embitterment scores for patients with high levels of both helplessness

Table III. Hierarchical regression analyses in 299 patients with rheumatic diseases after a disability pension examination who had been employed during the previous year. Embitterment is predicted from 1) demographic variables, 2) helplessness and invalidation (top: discounting, bottom: lack of understanding), and 3) the interaction of helplessness and invalidation.

	b	SE b	β	*p*	ΔR^2	*p*
Demographic variables						
Block 1					0.06	¥
Female gender	-0.27	0.12	-0.14	*		
Age	-0.01	0.01	-0.12	*		
Marital status - single	-0.10	0.23	-0.04			
Marital status - partnered	-0.35	0.17	-0.16	*		
Work - part-time	0.11	0.23	0.07			
Work - unemployed	0.35	0.23	0.21			
Discounting						
Block 2					0.27	•
Female gender	-0.25	0.10	-0.13	*		
Age	0.002	0.01	0.02			
Marital status - single	-0.11	0.19	-0.04			
Marital status - partnered	-0.29	0.15	-0.13			
Work - part-time	0.02	0.20	0.01			
Work - unemployed	0.02	0.19	0.01			
Discounting	0.27	0.04	0.32	•		
Helplessness	0.09	0.01	0.39	•		
Block 3					0.02	¥
Female gender	-0.25	0.10	-0.13	*		
Age	0.003	0.01	0.03			
Marital status - single	-0.13	0.19	-0.05			
Marital status - partnered	-0.32	0.15	-0.15	*		
Work - part-time	0.05	0.20	0.03			
Work - unemployed	0.04	0.19	0.02			
Discounting	0.25	0.04	0.30	•		
Helplessness	0.09	0.01	0.38	•		
Discounting x helplessness	0.03	0.01	0.14	¥		
Lack of understanding						
Block 2					0.25	•
Female gender	-0.26	0.11	-0.14	*		
Age	-0.002	0.01	-0.02			
Marital status - single	-0.10	0.19	-0.02			
Marital status - partnered	-0.31	0.15	-0.14	*		
Work - part-time	0.001	0.20	0.001			
Work - unemployed	0.03	0.20	0.02			
Lack of understanding	0.24	0.04	0.28	•		
Helplessness	0.10	0.01	0.43	•		
Block 3					0.02	¥
Female gender	-0.29	0.10	-0.15	¥		
Age	-0.001	0.01	-0.01			
Marital status - single	-0.07	0.19	-0.02			
Marital status - partnered	-0.30	0.15	-0.14	*		
Work - part-time	0.04	0.20	0.02			
Work - unemployed	0.07	0.19	0.04			
Lack of understanding	0.23	0.04	0.27	•		
Helplessness	0.10	0.01	0.43	•		
Lack of understanding x helplessness	0.03	0.01	0.14	¥		

Note. ΔR^2 change in adjusted R^2 and significance levels of F-change.
*$p<0.05$; ¥$p<0.01$; •$p<0.001$.

and invalidation. At low levels of helplessness (1 SD below the mean), a small difference in embitterment (*d*=0.38) was observed between people low and high on discounting, whereas at high levels of helplessness (1 SD above the mean) the difference between patients low and high on discounting was large (*d*=0.86) (Fig. 1, left panel). Similarly, at low levels of helplessness, the difference in embitterment between people low and high on lack of understanding was small (*d*=0.26), whereas at high levels of helplessness the difference between patients low and high on lack of understanding was large (*d*=0.83) (Fig. 1, right panel). Simple slope analyses showed significant slopes for helplessness in case of low (t=3.70, $p<0.001$) and high levels of discounting (t=7.89, $p<0.001$), and in case of low (t=4.39, $p<0.001$) and high (t=8.22, $p<0.001$) levels of lack of understanding.

Discussion

The present study examined the occurrence and possible determinants of embitterment in patients with rheumatic diseases after a disability pension examination. About one out of five patients had a high – possibly problematic – embitterment score. Both helplessness, invalidation at work, and particularly their joint effect were associated with high embitterment scores.

The occurrence of embitterment in patients who applied for disability pension was high as compared to the general population and working reference patients. Psychological factors are among the strongest predictors of disability in patients with musculoskeletal diseases (17-19). As compared to related conditions such as depression and anxiety, embitterment has received little attention in research (20, 21). However, embitterment covers a serious emotional-motivational disorder that is typically triggered in response to negative events, such as a chronic rheumatic disease and unemployment, and embitterment is both conceptually and empirically distinct from depression or anxiety (22). As embittered patients tend to cling to their own point of view in order to convince themselves and others of the strength of their cause instead of adapting to the changed situation (3), it often shows a progressive course that may hinder well-being, functioning, and reintegration to work. This is a burden to the patient, the family of the patient, and it is an economic burden to society at large (23, 24).

Helplessness was associated with embitterment even after controlling for other variables. Helpless patients feel incapable of mastering their (aversive) situation either cognitively or behav-

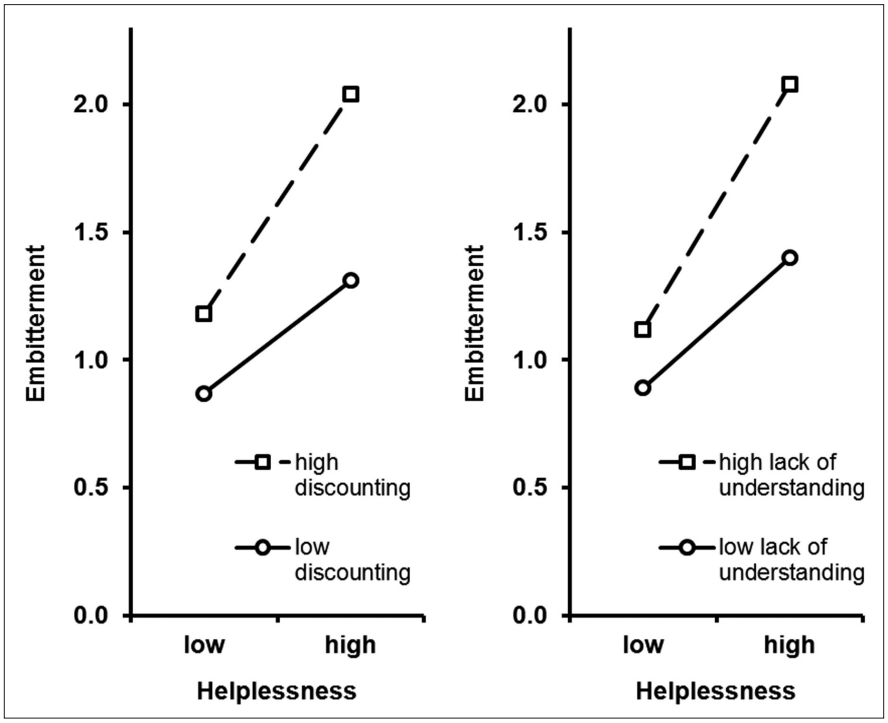

Fig. 1. Embitterment predicted by helplessness combined with discounting (left) and lack of understanding (right).

iourally (9, 10). Helplessness may be targeted with cognitive-behavioural techniques that empower patients to overcome their situation rather than resorting in maladaptive defenses. An internet-based intervention has been developed to empower patients specifically with regard to their disability examination through increasing knowledge, self-awareness, expectations, self-efficacy, and active participation (25). Although the satisfaction with this intervention was high, the reach, compliance, and impact of the intervention were found to be poor (26). This suggests that attention is needed to not only help but also reach patients who are helpless.

Illness invalidation at work was especially associated with more embitterment in patients high in helplessness. Illness invalidation encompasses a wide range of experiences that are affect patients, such as being disqualified as a maligner, being denied emphatic concern, or lack of understanding that the patient can do much more on some days than on other days (27). In patients who feel both helpless and invalidated, the embittered act of dismissing perceived wrongdoers may be a final means to secure one's integrity and claim support (4, 28, 29). Apart from empowering patients to master invalidating situations, which may be done with cognitive-behavioural therapy, or perhaps with forgiveness or wisdom-based techniques (30, 31), another prevention strategy is educating people in the work environment about the consequences of rheumatic illnesses, and about patient's valid needs for suitable work attuned to the patients' needs (32). In everyday clinical and vocational practice, providing a sense of unconditional acceptance of the patient's view may help embittered patients to lower their defenses (11). In conclusion, we argue that efforts to prevent embitterment should target both the work environment and the coping ability of patients.

Embitterment and one of its core elements perceived injustice have been neglected in biopsychosocial models of disability in rheumatic diseases. In individuals with injury-related musculoskeletal problems, two dimensions of perceived injustice have been identified: appraised irreparability of loss and other-blame (5). Appraised irreparability is close to our helplessness construct whereas other-blame is close to our perceived invalidation construct. The present results support the notion that these two factors, and especially their combination, contribute to embitterment.

Several study limitations should be considered. First, given the low response rate (26%), we cannot exclude the possibility that our results are affected by self-selection bias. That said, the recruitment of respondents was similar to the recruitment of respondents in the reference patient groups. Second, our findings with respect to illness invalidation do not generalise beyond patients who had been employed within the past year. Third, our cross-sectional design hampers insight into the causality of associations between invalidation, helplessness and embitterment. Thus, embitterment could be due to personal factors such as helplessness and process factors of the disability pension examination or work such as invalidation, and likely to both individual and environmental factors as our study suggested. Fourth, several variables that might potentially influence the psychological status such as pharmacotherapy, psychotherapy, or exercise therapy were not investigated and are difficult to investigate specific therapies are more prevalent in specific diseases and depend on disease-severity. Fifth, longitudinal studies could test the hypothesis that embitterment hampers adjustment to disability by being less able to find suitable work or pursuing another life course.

To conclude, our results suggest that, after a disability pension examination, embitterment is present in one out of every five patients with a rheumatic disease. This condition may prevent the finding of employment or having a valued life without work. To the extent that helplessness and invalidation at work are causal determinants of embitterment, interventions targeting these aspects might prevent and reduce embitterment.

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