Analysis of patient-physician discrepancy in global assessment of systemic autoimmune myopathy disease activity

R.A. Cordeiro[1], F.M. Fischer[2], S.K. Shinjo[1]

[1]Rheumatology Division, Faculdade de Medicina FMUSP, [2]Department of Environmental Health, Faculdade de Saude Publica, Universidade de Sao Paulo, SP, Brazil.

Abstract

Objective

To compare the perception of disease activity (DA) between adult patients with systemic autoimmune myopathies (SAMs) and their physicians, and analyse possible sources of discordance.

Methods

This cross-sectional study included 75 patients with SAMs. Patients and physicians rated the global DA on a 0-10 cm visual analogue scale. A discrepancy score was calculated by subtracting physician assessment from patient assessment. Three groups were defined: (I) no discrepancy: difference within -2.0 to +2.0; (II) negative discrepancy (ND): difference <-2.0 (patient underrated DA in relation to physcian); (III) positive discrepancy (PD): difference >+2.0 (patient overrated DA in relation to physician). Logistic regression was used to identify predictors of discordance.

Results

Discordance in patient-physician assessment of DA was found in 21 (28%) cases. ND was observed in 3 (4%), PD in 18 (24%), and no discrepancy in 54 (72%) assessments. Due to the small number, ND cases were excluded from the analysis. PD was associated with older age, personal history of depression, past joint involvement, higher MMT-8 and lower extramuscular DA. In the regression model, for each additional year of age, the chance of PD increases, on average, by 9% (OR 1.09; 95%CI 1.01-1.17, p=0.034). Personal history of depression increases the chance of PD by 829% (OR 9.29; 95%CI 1.52-56.89, p=0.016).

Conclusion

Almost 30% of patients had discordance in DA assessment from their physicians. The majority of them overrated their DA. These patients tend to be older and are more likely to have personal history of depression, past joint involvement, and milder disease.

Key words

dermatomyositis, polymyositis, myositis, self-assessment, visual analogue scale, patient-reported outcome measures, health status

Rafael A. Cordeiro, MD
Frida M. Fischer, BSc, PhD
Samuel K. Shinjo, MD, PhD

Please address correspondence to:
Rafael A. Cordeiro,
Av. Dr Arnaldo 455, 3 andar, sala 3184,
CEP 01246-903, Cerqueira Cesar,
SP, Brazil.
E-mail: rafael19abc@hotmail.com

Received on October 12, 2021; accepted in revised form on January 4, 2022.

Funding: this work was supported by Fundação de Amparo à Pesquisa do Estado de São Paulo (FAPESP) no. 2019/11776-6; Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) no. 303379/2018-9, and Faculdade de Medicina da USP to S.K. Shinjo.

Competing interests: none declared.

Introduction

Systemic autoimmune myopathies (SAMs) comprise a group of rare autoimmune diseases that have skeletal muscle weakness as the main clinical feature. The group comprises dermatomyositis, polymyositis, antisynthetase syndrome, inclusion body myositis, immune-mediated necrotising myopathies, among others (1). Extramuscular involvement (cutaneous, articular, pulmonary, cardiac and gastrointestinal) can also occur and is an important contributor to morbidity and mortality of these patients (1, 2).

Accurate assessment of disease activity in patients with SAMs is crucial for guiding medical care. It is usually based on a set of parameters. Since there is no single indicator that translates diasease activity accurately, physicians rely on a combination of clinical features and laboratory tests to assess disease status and direct therapy. In addition to these parameters, there is growing understanding that patient reported outcomes should be incorporated into routine clinical practice (3).

An important step towards the standardisation of disease status assessment in patients with SAMs was the development of core set measures (for disease activity and damage) by the International Myositis Assessment & Clinical Studies Group (IMACS) (4, 5). This collaborative group has also developed preliminar definitions of improvement to be considered as endpoints for clinical trials and research studies (6, 7). Along with strength, functional, and cutaneous assessment tools, the IMACS Disease Activity Core Sets Measures includes the Patient Global Activity Assessment Score and the Physician Global Activity Assessment Score. These scores are expected to gauge the global evaluation of overall disease activity through a 10 cm visual analogue scale (VAS), which is anchored at the endpoints and the middle (5, 8).

In order to complete the global activity assessment, adult patients with SAMs are asked to take into consideration an overall rating of the inflammatory activity related to myositis at present, which can potentially improve with treatment. On the other hand, physicians should take into account all the information available at the time of the medical appointment such as medical history, physical examination, laboratory testing, and the current therapy needed (5, 8).

Studies analysing differences between patient and physician perceptions of disease activity have been conducted in many autoimmune rheumatic conditions such as systemic lupus erythematosus (9-11), rheumatoid arthritis (12, 13), and psoriatic arthritis (14). In the group of myositis, this topic has been studied for juvenile dermatomyositis (15). All these studies revealed a considerable degree of discordance between patient and physician assessment of health status and found a range of factors that would be associated with these discrepancies.

In this study, we contrasted patient and physician global assessment of systemic autoimmune myopathy disease activity so as to find the level of discrepancy and possible predictors of discordance.

Material and methods

Setting and study population

This is a single-centre cross-sectional study that included adult patients (18-60 years) with physician-diagnosed systemic autoimmune myopathy classified according to the 2017 EULAR/ACR classification criteria for idiopathic inflammatory myopathies (16). Patients were subclassified into polymyositis, dermatomyositis, clinically amyopathic dermatomyositis (2017 EULAR/ACR classification criteria) (16), anti-synthetase syndrome (criteria used by Behrens Pinto *et al.*) (17), and immune-mediated necrotising myopathy (224th ENMC International Workshop) (18).

Patients in regular follow-up were recruited from the outpatient clinic of the Rheumatology Division of a public tertiary center over a 6-month period (September 2019 to March 2020). Exclusion criteria were: patients diagnosed with inclusion body myositis, patients with cancer-associated myositis, and overlap syndromes (systemic autoimmune myopathy associated to any other systemic autoimmune rheumatic disease).

Definition of discordance in patient-physician global activity assessment scores

Patients rated their level of disease activity on a standard 10 cm VAS in which 0 means no evidence of disease activity and 10 means extreme or maximum disease activity. Following the IMACS form (4, 5), patients were asked to rate their overall disease activity (active inflammation, which can improve when treated with medicines) considering all the ways that myositis affects them. The physician global assessment of disease activity was performed on a separate VAS after completing the patient clinical and laboratory evaluation. Patients and physicians rated the overall disease activity on the same day and they were blind to each other's assessment.

There is no standardisation defining concordant or discordant scores when comparing patients and physicians global activity assessments obtained through VAS (13). On the basis of prior studies, particularly of the study that assessed juvenile dermatomyositis, we considered a difference greater than 2.0 cm between patient and physician VAS as discordant (15, 19).

Based on this definition, a discordance score was calculated by subtracting physician global assessment of disease activity from patient global assessment of disease activity. Then patients were divided into three groups: (1) no discordance when patient and physician assessments of disease activity were within 2.0 cm from each other ($-2.0 \leq \Delta \leq 2.0$); (2) negative discordance when the patient's assessment was underestimated ($\Delta > -2.0$) relative to the physician's (physician perceives greater disease activity than the patient); and (3) positive discordance when the patient's assessment was overestimated ($\Delta > 2.0$) relative to the physician's (patient perceives greater disease activity than the physician).

Socioeconomic-demographic, clinical and laboratory variables

Patient data were obtained through a structured questionnaire at study visit for the following: age, sex, ethnicity, level of education and monthly income. Patients were called to a separate room to fill in personal information and the patient's VAS of global activity. In case of doubts or difficulties, the patient could request the researcher's assistance (RAC) for clarification. The same investigator checked the questionnaires to make sure there was no missing data that could be readily filled in by the patient. Body mass index was calculated using anthropometric measurements obtained on the day of patient's inclusion in the study.

The following information was obtained through electronic medical record: disease duration, extramuscular manifestations (cutaneous, articular and/or pulmonary), current dose of glucocorticoids, the most recent creatine phosphokinase value (<6 months), and the record of any of the following comorbidities: systemic arterial hypertension, diabetes mellitus, anxiety, depression, hypothyroidism. Regarding extramuscular manifestations, we considered the following parameters: cutaneous manifestation (heliotrope rash, Gottron's papules, "mechanic's hands" or cutaneous calcinosis), joint manifestation (history of arthritis documented by a physician), pulmonary manifestation (alveolitis evidenced by computed tomography scan and pulmonary function test with forced vital capacity <70% of the predicted value and/or carbon monoxide diffusion capacity <70% of the predicted value).

The clinical assessment included a series of medical assessments of disease activity of various organ systems via the Myositis Disease Activity Assessment Visual Analogue Scales (MYOACT) (20). The score of the Manual Muscle Testing (MMT-8) (21) was obtained through the physical exam; this score is registered as part of the standard visit from patients seen at our myositis clinic. Both MYOACT and MMT-8 are part of the Myositis Disease Activity Assessment Tool recommended by the IMACS (5).

Patients were evaluated by one of the 24 rheumatology resident physicians at our institution. All rheumatology resident physicians had at least 6 months of field training. If in doubt to complete any of the forms, resident physicians could ask the senior rheumatologist (SKS) to verify the metrics and give his final impression. The senior rheumatologist is responsible for discussing the cases of patients with myositis and was also blinded to the patient's VAS of global activity.

Statistical analysis

Mean and standard deviation or median and interquartile range (25^{th}–75^{th}) were calculated for continuous variables. Median and interquartile range were presented for variables with non-normal distribution based on the Kolmogorov-Smirnov test. Categorical variables were presented as frequencies and proportions. In the univariate analysis, to compare the quantitative variables between two groups (concordance *vs*. discordance) the Student's *t*-test or the Wilcoxon-Mann-Whitney test was used. For categorical variables, groups were compared using Fisher's exact test or the chi-square test.

To estimate the probability of the patient disagreeing with the medical evaluation in relation to disease activity, the binomial logistic regression model was used. Initially, variables found to be significant at the 20% level ($p<0.20$) were tested in the model. Then, the preselected variables with significance level above 5% were consecutively removed from the model, leaving only those with significance levels below 5% ($p<0.05$) in the final model. In all stages, tests were carried out to verify the existence of multicollinearity. The 95% confidence intervals were also calculated. Statistical analysis was performed using the statistical software R 4.0.2 (R Core Team, 2020).

Ethical approval

This study was approved by local research ethics committee (CAAE 11043419.8.1001.0068) and all participants signed the consent form.

Results

A total of 75 patients with SAMs were initially enrolled. Discordance between physician global assessment of disease activity and patient global assessment of disease activity (difference greater than 2.0 points) was found in 28% (n=21) of the cases. Of these, 4% (n=3) presented

Table I. Baseline data of patients included in the analysis.

Variable	n=72
Age (years)	44.3 ± 9.5
Female gender	49 (68.1)
Ethnicity	
Caucasian	21 (29.2)
Other (Black, Asian, Indigenous, and other)	51 (70.8)
Body mass index (kg/m^2)	29.9 ± 6.1
Formal education time	
≤9 years	19 (26.4)
>9 and ≤12 years	32 (44.4)
>12 years	21 (29.2)
Monthly income	
≤1 minimum wage	37 (51.4)
>1 and ≤3 minimum wages	23 (31.9)
>3 minimum wages	12 (16.7)
Myositis subtype	
Dermatomyositis	15 (20.8)
Clinically amyopathic dermatomyoitis	19 (26.4)
Antisynthetase syndrome	27 (37.5)
Polymyositis	5 (6.9)
Immune-mediated necrotising myopathy	6 (8.3)
Disease duration (years)	6.1 ± 4.5
Patients with ≥1 extramuscular manifestation	62 (86.1)
Cutaneous manifestation	55 (76.4)
Arthritis	30 (41.7)
Pulmonary manifestation	32 (44.4)
Daily dose of prednisone or equivalent	0.0 [0.0-10.0]
Creatine phosphokinase serum level	190 [82-578]
Systemic arterial hypertension	30 (41.7)
Diabetes mellitus	12 (16.7)
Anxiety	11 (15.3)
Depression	7 (9.7)
Hypothyroidism	5 (6.9)
MMT-8 (0-80)	80 [78-80]
MYOACT score	
Constitutional VAS (0-10 cm)	0.0 [0.0-1.2]
Cutaneous VAS (0-10 cm)	0.0 [0.0-0.9]
Skeletal VAS (0-10 cm)	0.0 [0.0-0.6]
Gastrointestinal VAS (0-10 cm)	0.0 [0.0-0.0]
Pulmonar VAS (0-10 cm)	0.0 [0.0-0.6]
Cardiac VAS (0-10 cm)	0.0 [0.0-0.0]
Extramuscular VAS (0-10 cm)	0.8 [0.0-2.3]
Muscular VAS (0-10 cm)	0.0 [0.0-1.2]

Data are expressed as frequency (%), mean ± standard deviation or median [interquarilte 25th - 75th]. VAS: Visual Analogue Scale; MMT-8: Manual Muscle Testing; MYOACT: Myositis Disease Activity Assessment Visual Analogue Scales.

negative discrepancy and 24% (n=18) had positive discrepancy (higher patient global assessment of DA). Due to the small number, negative discrepancy cases were excluded from the analysis. Sociodemographic and clinical data of patients included in the analysis (n=72) are shown in Table I.

The median score (VAS 0–10 cm) of physician global assessment of DA was 1.2 [0.0–4.0] and the median score (VAS 0–10 cm) of patient global assessment of DA was 3.8 [1.0–5.4].

In the univariate analysis, positive discrepancy was associated with: older age (p=0.012), past joint involvement - arthritis (p=0.025), personal history of depression (p=0.009), higher MMT-8 score (p=0.035) and lower VAS score for extramuscular disease activity (p=0.033). The comparison between groups (concordance *vs*. positive discordance) is shown in Table II.

In the logistic regression model, each additional year of age was associated with a 9% increase in the odds of positive discordance (OR = 1.09), while the personal history of depression was associated with an increase in the chance of positive discrepancy by 829% (OR = 9.29), as shown in Table III.

Discussion

Our data show that patients and physicians rate myositis disease activity differently in more than a quarter of the cases. As expected, patients tended to score higher than physicians in their assessment. In this study, positive discordance was associated with older age, personal history of depression, past joint involvement, higher MMT-8 and lower extramuscular disease activity.

The discrepancy between patients and physicians global disease activity has been analysed for some autoimmune rheumatic diseases, mainly in rheumatoid arthritis and systemic lupus erythematosus (9-13, 19, 22); however, this issue has not been consistently explored in adult patients with systemic autoimmune myopathies. In this study focused on a well-characterised sample of outpatients with myositis, it was found discordance between the visual analogue scale for global disease activity reported by patients and physicians in 28% of the cases. The cut-off of 2.0 points difference used to define discordance between patient-physician assessments was chosen taking into consideration published studies on similar topics (14, 15, 19), including a recent study which analysed patient/family and physician discordance of global disease assessment in juvenile dermatomyositis (15). However, this cut-off of 2.0 points difference is not standardised in the literature, and there are studies in immune-mediated rheumatic diseases that considered other values to define discordance between patient-physician assessments (9, 12, 22).

The majority of the myositis patients in this study rated themselves similarly to their treating physicians, since 72% of the absolute VAS differences regarding global disease activity were below 2.0 cm. In line with previous reports on autoimmune rheumatic diseases other than SAMs (9, 12, 14, 19, 22-24), we found that patients tended to score as doing worse compared to their physician when discordance was present (24% of positive discordance *vs*. 4% of negative discordance).

Table II. Variables influencing the discordance score - univariate analysis.

Variable	Concordance (n=54)	Discordance (n=18)	*p*-value
Age (years)	42.8 ± 9.4	48.9 ± 8.2	0.012
Female gender	35 (64.8)	14 (77.8)	0.390
Ethnicity			
Caucasian	15 (27.8)	6 (33.3)	0.766
Other (Black, Asian, Indigenous, and other)	39 (72.2)	12 (66.7)	
Body mass index (kg/m^2)	29.9 ± 6.6	29.7 ± 4.6	0.849
Formal education time			
≤9 years	12 (22.2)	7 (38.9)	0.216
>9 and ≤12 years	27 (50.0)	5 (27.8)	
>12 years	15 (27.8)	6 (33.3)	
Monthly income			
≤1 minimum wage	27 (50.0)	10 (55.6)	0.900
>1 and ≤3 minimum wages	18 (33.3)	5 (27.8)	
>3 minimum wages	9 (16.7)	3 (16.7)	
Myositis subtype			
Dermatomyositis	14 (25.9)	1 (5.6)	0.122
Clinically amyopathic dermatomyoitis	13 (24.1)	6 (33.3)	
Antisynthetase syndrome	17 (31.5)	10 (55.6)	
Polymyositis	4 (7.4)	1 (5.6)	
Immune-mediated necrotising myopathy	6 (11.1)	0	
Disease duration (years)	5.6 ± 3.7	7.7 ± 6.4	0.198
Patients with ≥1 extramuscular manifestation	45 (83.3)	17 (94.4)	0.434
Cutaneous manifestation	41 (75.9)	14 (77.8)	1.000
Arthritis	18 (33.3)	12 (66.7)	0.025
Pulmonary manifestation	23 (42.6)	9 (50.0)	0.597
Daily dose of prednisone or equivalent	0.0 [0.0-10.0]	0.0 [0.0-11.2]	0.472
CPK level	208 [84-595]	113 [79-361]	0.380
Systemic arterial hypertension	21 (38.9)	9 (50.0)	0.423
Diabetes mellitus	9 (16.7)	3 (16.7)	1.000
Anxiety	10 (18.5)	1 (5.6)	0.271
Depression	2 (3.7)	5 (27.8)	0.009
Hypothyroidism	5 (9.3)	0	0.322
MMT-8 (0-80)	80 [78-80]	80 [80-80]	0.035
MYOACT score			
Constitutional VAS (0-10 cm)	0.0 [0.0-2.0]	0.0 [0.0-0.4]	0.180
Cutaneous VAS (0-10 cm)	0.0 [0.0-1.0]	0.0 [0.0-0.2]	0.144
Skeletal VAS (0-10 cm)	0.0 [0.0-0.6]	0.0 [0.0-0.4]	0.525
Gastrointestinal VAS (0-10 cm)	0.0 [0.0-0.0]	0.0 [0.0-0.0]	0.320
Pulmonar VAS (0-10 cm)	0.0 [0.0-0.9]	0.0 [0.0-0.0]	0.236
Cardiac VAS (0-10 cm)	0.0 [0.0-0.0]	0.0 [0.0-0.0]	0.189
Extramuscular VAS (0-10 cm)	1.0 [0.0-3.3]	0.0 [0.0-1.4]	0.033
Muscular VAS (0-10 cm)	0.0 [0.0-1.8]	0.0 [0.0-0.1]	0.254

Data are expressed as frequency (%), mean ± standard deviation or median [interquartile 25th - 75th]. VAS: Visual Analogue Scale; MMT-8: Manual Muscle Testing; MYOACT: Myositis Disease Activity Assessment Visual Analogue Scales.

Table III. Variables influencing the discordance score – multivariate analysis.

Variable	Estimate	OR	95%CI	*p*-value
Intercept	-5.20			0.006
Age	0.08	1.09	1.01-1.17	0.034
Depression	2.23	9.29	1.52-56.89	0.016

OR: odds ratio; CI: confidence interval.

Among the possible determining factors of dicrepancy, we showed that past joint involvement with arthritis, greater muscle strength (graded in the manual muscle testing) and lower extramuscular disease activity (measured on a 0-10 cm VAS by the physician) were associated with positive discordance in the assessments. The older age and the personal history of depression were the major determinants of patient's overestimation of their global disease activity in the multivariate model.

Interestingly, a large registry study with patients who met probable or definite criteria for myositis identified that joint involvement was significantly associated with worse physical component summary as well as with lower scores in the mental component summary of the Short Form 12 (SF-12) health-related quality of life survey questionnaire (25). We hypothesise that this influence on quality of life, both in the physical and mental domains, may also lead to a worse perception of disease activity in patients with previous joint involvement, even if objectively in current remission. The past and ongoing joint involvement has also been demonstrated to be one of the determinants of patient-physician discordance regarding the lupus low disease state concept for patients with systemic lupus erythematosus (11).

In this study, parameters of milder disease state (*e.g.* higher MMT-8 score and lower VAS score for extramuscular disease activity) were also associated with positive discrepancy in the assessment of global disease activity. It suggests that other factors than the severity of the disease are associated with a worse perception of disease activity by patients. Indeed, our multivariate regression analysis gave us useful insights into variables that are not purely linked to disease activity, but that seem to exert a great influence on the patient's perception of being worse off than considered by their physician. Our findings suggest that increasing age (but not disease duration) and a history of depression are independent predictors for patients to perceive higher disease activity than their treating physicians.

Regarding the increasing age, it has already been demonstrated to be associated with worse physical component summary score of quality of life in patients with idiopathic inflammatory miopathies, which might influence a poorer perception of disease activity. However, the mentioned study included patients with sporadic inclusion

body myositis in almost 30% of the sample, not limiting the age of participants over 18 years. In our study, we focused on adult patients, including only participants aged 18 to 60 years; and we decided not to enroll patients with inclusion body myositis, who tend to be elderly, with a distinctive pattern of clinical presentation and muscle involvement (26).

Finally, a history of depression assessed by reviewing the medical records was associated with an increase of 829% in the odds of positive discordance (compared to the absence of discordance). This finding focuses great importance on the need of a better understanding of factors that affect the mental health of myositis patients. In accordance with our results, higher levels of depressive symptoms have been shown to be the strongest determinant of patient-physician discordance in rheumatoid arthrits disease activity assessment, with higher patient rating (27). However, a limitation of our study was that it assessed comorbidities, including mental disorders, through the analysis of medical records, which may not be accurate to reflect the severity of depressive symptoms by the time of the patient enrollment. We acknowledge that the use of validated instruments to screen for anxiety and depression such as the Hospital Anxiety and Depression Scale, the Beck Anxiety Inventory or the Beck Depression Inventory would have been ideal (28, 29).

Moreover, we have not performed analysis of physician characteristics such as age and gender that might have an influence on how physicians subjectively assess disease activity. Other limitations of this study should be acknowledged: the convenience sample; the cross-sectional design, which is not able to capture the variation in patients' perceptions as the disease improves or worsens; and the tertiary center setting, that may not be representative of the general population with myositis.

Understanding the factors related to patient-physician discordance in overall activity of autoimmune rheumatic diseases may improve doctor-patient relationship, patient satisfaction and compliance, which would facilitate disease managemet and shared decisions. Further research is needed to clarify whether patient-physician discordance on disease activity impacts long-term clinical outcomes and whether interventions to bring together patient-provider perspectives would improve outcomes and patient care in the context of systemic autoimmune myopathies.

References

1. ZONG M, LUNDBERG IE: Pathogenesis, classification and treatment of inflammatory myopathies. *Nat Rev Rheumatol* 2011; 7: 297-306.
2. ODDIS CV, AGGARWAL R: Treatment in myositis. *Nat Rev Rheumatol* 2018; 14: 279-89.
3. DIRENZO D, BINGHAM CO, MECOLI CA: Patient-reported outcomes in adult idiopathic inflammatory myopathies. *Curr Rheumatol Rep* 2019; 21: 62.
4. MILLER FW, RIDER LG, CHUNG Y *et al*.: Proposed preliminary core set measures for disease outcome assessment in adult and juvenile idiopathic inflammatory myopathies. *Rheumatology* (Oxford) 2001; 40: 1262-73.
5. RIDER LG, WERTH VP, HUBER AM *et al*.: Measures of adult and juvenile dermatomyositis, polymyositis, and inclusion body myositis: Physician and Patient/Parent Global Activity, Manual Muscle Testing (MMT), Health Assessment Questionnaire (HAQ)/ Childhood Health Assessment Questionnaire (C-HAQ), Childhood Myositis Assessment Scale (CMAS), Myositis Disease Activity Assessment Tool (MDAAT), Disease Activity Score (DAS), Short Form 36 (SF-36), Child Health Questionnaire (CHQ), physician global damage, Myositis Damage Index (MDI), Quantitative Muscle Testing (QMT), Myositis Functional Index-2 (FI-2), Myositis Activities Profile (MAP), Inclusion Body Myositis Functional Rating Scale (IBMFRS), Cutaneous Dermatomyositis Disease Area and Severity Index (CDASI), Cutaneous Assessment Tool (CAT), Dermatomyositis Skin Severity Index (DSSI), Skindex, and Dermatology Life Quality Index (DLQI). *Arthritis Care Res* (Hoboken) 2011; 63 (Suppl. 11): S118-57.
6. RIDER LG, GIANNINI EH, BRUNNER HI *et al*.: International consensus on preliminary definitions of improvement in adult and juvenile myositis. *Arthritis Rheum* 2004; 50: 2281-90.
7. RIDER LG, GIANNINI EH, HARRIS-LOVE M *et al*.: Defining clinical improvement in adult and juvenile myositis. *J Rheumatol* 2003; 30: 603-17.
8. RIDER LG, AGGARWAL R, MACHADO PM *et al*.: Update on outcome assessment in myositis. *Nat Rev Rheumatol* 2018; 14: 303-18.
9. YEN JIMC, ABRAHAMOWICZ M, DOBKIN PL, CLARKE ANNE, BATTISTA RN, FORTIN PR: Determinants of discordance between patients and physicians in their assessment of lupus disease activity. *J Rheumatol* 2003; 30: 1967-76.
10. ALARCON GS, MCGWIN G, BROOKS K *et al*.: Systemic lupus erythematosus in three ethnic groups. XI. Sources of discrepancy in perception of disease activity: a comparison of physician and patient visual analog scale scores. *Arthritis Rheum* 2002; 47: 408-13.
11. ELEFANTE E, TANI C, STAGNARO C *et al*.: Articular involvement, steroid treatment and fibromyalgia are the main determinants of patient-physician discordance in systemic lupus erythematosus. *Arthritis Res Ther* 2020; 22: 214.
12. NICOLAU G, YOGUI MM, VALLOCHI TL, GIANINI RJ, LAURINDO IMM, NOVAES GS: Sources of discrepancy in patient and physician global assessments of rheumatoid arthritis disease activity. *J Rheumatol* 2004; 31: 1293-6.
13. DESTHIEUX C, HERMET A, GRANGER B, FAUTREL B, GOSSEC L: Patient-physician discordance in global assessment in rheumatoid arthritis: a systematic literature review with meta-analysis. *Arthritis Care Res* 2016; 68: 1767-73.
14. EDER L, THAVANESWARAN A, CHANDRAN V, COOK R, GLADMAN DD: Factors explaining the discrepancy between physician and patient global assessment of joint and skin disease activity in psoriatic arthritis patients. *Arthritis Care Res* (Hoboken) 2015; 67: 264-72.
15. TORY H, ZURAKOWSKI D, KIM S *et al*.: Patient and physician discordance of global disease assessment in juvenile dermatomyositis: findings from the Childhood Arthritis & Rheumatology Research Alliance Legacy Registry. *Pediatr Rheumatol Online J* 2020; 18: 5.
16. LUNDBERG IE, TJÄRNLUND A, BOTTAI M *et al*.: 2017 European League Against Rheumatism/American College of Rheumatology Classification Criteria for Adult and Juvenile Idiopathic Inflammatory Myopathies and Their Major Subgroups. *Arthritis Rheumatol* 2017; 69: 2271-82.
17. BEHRENS PINTO GL, CARBONI RC DE S, DE SOUZA FHC, SHINJO SK: A prospective cross-sectional study of serum IL-17A in antisynthetase syndrome. *Clin Rheumatol* 2020; 39: 2763-71.
18. ALLENBACH Y, MAMMEN AL, BENVENISTE O *et al*.: 224th ENMC International Workshop: Clinico-sero-pathological classification of immune-mediated necrotizing myopathies Zandvoort, The Netherlands, 14–16 October 2016. *Neuromuscul Disord* 2018; 28: 87-99.
19. KHAN NA, SPENCER HJ, ABDA E *et al*.: Determinants of discordance in patients' and physicians' rating of rheumatoid arthritis disease activity. *Arthritis Care Res* (Hoboken) 2012; 64: 206-14.
20. SULTAN SM, ALLEN E, ODDIS CV *et al*.: Reliability and validity of the myositis disease activity assessment tool. *Arthritis Rheum* 2008; 58: 3593-9.
21. HARRIS-LOVE MO, SHRADER JA, KOZIOL D *et al*.: Distribution and severity of weakness among patients with polymyositis, dermatomyositis and juvenile dermatomyositis. *Rheumatology* (Oxford) 2009; 48: 134-9.
22. GUIMARÃES MFBR, PINTO MRC, RESENDE GG *et al*.: Discordance between the patient's and physician's global assessment in rheumatoid arthritis: Data from the REAL study-Brazil. *PLoS One* 2020; 15: e0230317.
23. CHALLA DN, KVRGIC Z, CHEVILLE AL *et al*.:

Patient-provider discordance between global assessments of disease activity in rheumatoid arthritis: A comprehensive clinical evaluation. *Arthritis Res Ther* 2017; 19: 212.
24. ELERA-FITZCARRALD C, VEGA K, GAMBOA-CÁRDENAS RV *et al*.: Discrepant perception of lupus disease activity: a comparison between patients' and physicians' disease activity scores. *J Clin Rheumatol* 2020; 26: S165-9.
25. FELDON M, FARHADI PN, BRUNNER HI *et al*.: Predictors of reduced health-related quality of life in adult patients with idiopathic inflammatory myopathies. *Arthritis Care Res* (Hoboken) 2017; 69: 1743-50.
26. CATALÁN M, SELVA-O'CALLAGHAN A, GRAU JM: Diagnosis and classification of sporadic inclusion body myositis (sIBM). *Autoimmun Rev* 2014; 13: 363-6.
27. BARTON JL, IMBODEN J, GRAF J, GLIDDEN D, YELIN EH, SCHILLINGER D: Patient-physician discordance in assessments of global disease severity in rheumatoid arthritis. *Arthritis Care Res* (Hoboken) 2010; 62: 857-64.
28. JULIAN LJ: Measures of anxiety: State-Trait Anxiety Inventory (STAI), Beck Anxiety Inventory (BAI), and Hospital Anxiety and Depression Scale-Anxiety (HADS-A). *Arthritis Care Res* (Hoboken) 2011; 63 (Suppl. 11): S467-72.
29. SMARR KL, KEEFER AL: Measures of depression and depressive symptoms: Beck Depression Inventory-II (BDI-II), Center for Epidemiologic Studies Depression Scale (CES-D), Geriatric Depression Scale (GDS), Hospital Anxiety and Depression Scale (HADS), and Patient Health Questionnaire-9 (PHQ-9). *Arthritis Care Res* (Hoboken) 2011; 63 (Suppl. 11): S454-66.