Development of the Myositis Activities Profile — Validity and Reliability of a Self-Administered Questionnaire to Assess Activity Limitations in Patients with Polymyositis/Dermatomyositis

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ABSTRACT. ***Objective.*** To develop a disease-specific questionnaire for assessing limitations in activities of daily life, the Myositis Activities Profile (MAP), and to investigate its validity and reliability.

Methods. Groups of 10, 27, 31, and 17 patients with polymyositis (PM) or dermatomyositis (DM) participated in different parts of the study. In the first draft of the MAP, patients rated their difficulty and experienced importance of selected activities from the International Classification of Impairments, Disabilities, and Handicaps (ICIDH)-2 Beta-2 draft. The 37 highest rated activities formed a second draft of the MAP, which was analyzed for internal redundancy and consistency. For construct validity a third draft was correlated with CPK levels, the Functional Index in myositis (FI), the Arthritis Impact Measurement Scales-2 (AIMS2), the Health Assessment Questionnaire (HAQ), and subjective global disease impact. Test-retest reliability over one week was investigated.

Results. There were several expected correlations ($r_s > 0.50$) between subscales of the MAP and corresponding subscales of the AIMS2, and a 31 item MAP correlated moderately with the HAQ ($r_s = 0.70$) and less with the FI ($r_s = 0.55$), subjective global disease impact ($r_s = 0.43$), and CPK levels ($r_s = 0.17$). No systematic differences were found between test and retest, and weighted kappa coefficients ranged from $K_w = 0.56$ to 0.77.

Conclusion. The MAP seems to be a valid and reliable method for assessing activity limitations in patients with PM and DM. (J Rheumatol 2002;29:2386–92)

Key Indexing Terms:
DAILY ACTIVITIES
DERMATOMYOSITIS
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QUESTIONNAIRE

Polymyositis (PM) and dermatomyositis (DM) are idiopathic inflammatory myopathies characterized by decreased muscle strength and endurance, general fatigue, and, in some cases, muscle pain and extramuscular involvement such as lung fibrosis[1]. Decreased cardiovascular fitness compared to healthy controls has also been reported[2]. Although there is often an initial positive response to first-line therapy of high dose corticosteroids, many patients do not fully respond to this treatment[3]. Increased disability over time in these patients has been reported[4]. One study describes that patients with PM and DM rated quality of life as "fairly good" or "very good," except for physical activities, which were rated as "poor" or "very poor"[5]. Systematic knowledge of the specific consequences of myositis in activities of daily life is poor.

A manual relating to the consequences of disease, the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH), was suggested by the World Health Organization in 1980[6]. The system underwent several revisions discussed under the acronym ICIDH-2 Beta-2 draft[7] until the new International Classification of Functioning, Disability, and Health (ICF) was approved in 2001[8]. In myositis, disease activity is often assessed with creatine phosphokinase (CPK) concentrations or muscle biopsies. Muscle strength and endurance are the most commonly evaluated impairments[9]. The Childhood Health Assessment Questionnaire (CHAQ) has been validated for patients with juvenile DM[10,11], and has also been used to describe disability in these patients[12]. Only one clinical trial involving patients with adult onset PM and DM has used the ability to perform daily activities as an outcome measure, a modified score calculated as the sum of 9 activities[13].

Numerous questionnaires have been developed to assess

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different aspects of health status. These instruments may be classified as generic or disease-specific. Generic instruments such as the Short Form 36 health survey[14], the Nottingham Health Profile[15], and the Sickness Impact Profile[16] may be used to evaluate different kinds of chronic conditions and also to compare them with other conditions or with general populations. Arthritis-specific instruments, such as the HAQ[17], the Arthritis Impact Measurement Scales[18], and their revision AIMS2[19], are more specifically directed toward populations with arthritis. They allow comparisons between different rheumatic diagnoses, but may not be sensitive enough to capture activity limitations caused by a specific nonarthritic condition. Systems have thus been developed or adapted for specific diagnoses such as ankylosing spondylitis[20-23], scleroderma[24], and juvenile chronic arthritis[25]. To our knowledge, no disease-specific systems for assessing limitations in daily activities have been developed for adult patients with PM or DM.

Our aim was to develop a disease-specific questionnaire to assess limitations, e.g., difficulty and importance, in daily activities of patients with PM and DM, and to investigate its test-retest reliability and some aspects of validity.

MATERIALS AND METHODS

Patients. Four samples of individuals with PM or DM were recruited for study at the Department of Rheumatology, Karolinska Hospital, Stockholm, Sweden. All patients with PM and DM at the clinic were invited to participate if they met the inclusion criteria: (1) speaking and understanding Swedish language well and (2) being able to perform the Functional Index (FI) in myositis. The first sample included 10 individuals strategically chosen to represent men and women of various ages, varying disease duration and severity of illness, and with various demands in daily activities as to work and family situation. The second sample consisted of 24 individuals, 7 of the previous 10 and another 17 with stable disease and unchanged medication for the previous 3 months. The third sample included 31 individuals in all stages of PM and DM, 16 from sample 2 and another 15. The fourth sample included the 17 individuals from the third sample with 3 months of stable disease activity and stable medication. Characteristics collected from patient files of the total 42 patients and the 4 samples are presented in Table 1.

Assessments. The AIMS2 consists of 52 questions divided into 12 different aspects of health — mobility, walking and bending, hand and finger function, arm function, self-care, household tasks, social activities, social support, pain, work, tension, and mood. Every subscale is scored 0–10, where 0 indicates normal function[19,26].

The Stanford Health Assessment Questionnaire Disability Index (HAQ) consists of 20 questions divided into 8 categories of activities — dressing and grooming, arising, eating, walking, hygiene, reach, grip, and other activity. The HAQ is scored from 0 to 3, where 3 indicates "unable to do"[17,27].

Subjective global disease impact was assessed on a 6 grade scale: 0 = no problems, 1 = very small problems, 2 = small problems, 3 = moderate problems, 4 = severe problems, and 5 = very severe problems[28].

The Functional Index in myositis (FI) measures the endurance of 11 muscle groups. Total score is 64 per right and left side[28]. In this study FI was modified to use the more reliable Grippit instrument[29] for measuring grip strength instead of the sphygmomanometer originally suggested in the FI[30].

Disease activity was assessed with CPK levels analyzed during the last month.

Development of the Myositis Activities Profile (MAP). The ICIDH-2 Beta-2 draft included 315 activities classified in 8 categories: (1) Activities of learning and applying knowledge (n = 26), (2) Communication activities (n = 47), (3) Movement activities (n = 41), (4) Activities of moving around (n = 24), (5) Self-care activities (n = 53), (6) Domestic activities (n = 37), (7) Interpersonal activities (n = 26), and (8) Performing tasks and major life activities (n = 61). All activities, considered by the research group to be relevant for people living in the Western world and congruent with the disease phenotype described for PM and DM, were selected. This procedure resulted in a number of activities, which were translated into Swedish by the research group and an English speaking bilingual professional. Two questions were formulated for each activity: "How difficult is it for you to...?" and "How important is it for you to be able to...?". Each of the 2 questions was accompanied by a numeric scale graded from 1 (no difficulty/not at all important) to 10 (impossible/very important).

For content validity, the first draft of the MAP was answered by patients in sample one, who were also invited to comment on the content and wording of each question, a procedure requiring about 45 minutes. The median of difficulty and importance was then pooled for each activity and those with a pooled median score ≥ 6 were retained for the second draft. The wording of the questions for each activity was then modified to include both difficulty and importance (How much trouble does... cause you in daily life?) and each was followed by one verbal rating scale ranging from 1 (no trouble at all) to 7 (impossible to do). In the second draft of the MAP, the questions were listed in subscales congruent with the categories of the ICIDH-2 Beta-2 draft.

The second draft of the MAP was filled out by patients in sample 2, who were also invited to comment on the content in an open question at the end. Internal redundancy and internal consistency within each subscale was then investigated. The third draft of the MAP was answered by patients in sample 3, who also, for construct validity purposes, performed the FI, rated subjective global disease impact, and filled out the AIMS2 and the HAQ. The 3 questionnaires were answered at home the same day or the day after in the evening, and were then mailed back to the clinic.

For test-retest purposes, on this occasion the fourth sample was also given a second copy of the MAP, draft 3, to be filled out at home in the evening one week later. The questionnaire was then mailed back to the clinic.

Statistical analyses. Nonparametric statistics were consistently used. Descriptive data are presented as medians with ranges. Spearman's correlation coefficient (r_s) was used to analyze internal redundancy and also to investigate the internal consistency, i.e., the correlation between individual items and their subscales after the actual item had been removed from the score; $r_s > 0.90$ were considered to indicate internal redundancy, and $r_s < 0.50$ to indicate poor internal consistency. r_s was also used in the analyses of construct validity. $r_s > 0.50 < 0.75$ was considered moderate to good correlation and $r_s > 0.75$ as very good to excellent correlation. The sign test was used to analyze systematic variations and the weighted kappa coefficient (K_w) to analyze systematic and random variations in the test-retest investigation. The minimum significance level was set to $p < 0.05$.

Ethical scrutiny. All patients gave their informed consent to participation and the ethical committee of the Karolinska Hospital approved the study.

RESULTS

Content validity. The first draft of the MAP included 81 activities from the ICIDH-2 Beta-2 draft: none from the 2 first categories, Learning and applying knowledge and Communication activities; 25 from Movement activities, 11 from Activities of moving around, 21 from Self-care activities, 17 from Domestic activities, 4 from Interpersonal activities, and 3 from Performing tasks and major life activities. Comments from the patients resulted in rewording of some

Table 1. Background characteristics of 42 patients in 4 samples.

	Sample 1, n = 10	Sample 2, n = 24	Sample 3, n = 31	Sample 4, n = 17	Total Sample, n = 42
Age, yrs, median (range)	52 (31–66)	60 (26–79)	56 (24–72)	58 (26–70)	57 (23–81)
Sex, F/M, n	8/2	17/7	23/8	11/6	31/11
Diagnosis, PM/DM, n	6/4	17/7	18/12	8/8	27/15
Other diagnosis, MCTD/SSc/SLE, n	1/0/0	0/1/0	1/1/0	1/1/0	2/1/0
Duration since diagnosis, mo, median (range)	36 (12–84)	48 (24–120)	60 (2–240)	60 (12–240)	48 (2–240)
Prednisone dose, mg/day, median (range)	5.75 (0.0–20.0)	2.50 (0.0–10.0)	6.00 (0.0–40.0)	3.75 (0.0–10.0)	5.00 (2.0–40.0)
CPK levels, µcat/l, median (range)	0.9 (0.8–11.4)	1.8 (0.4–38.8)	1.6 (0.5–25.3)	1.6 (0.9–11.0)	2.0 (0.4–38.1)
Working					
Full-time, n	2	3	3	3	3
Part-time, n	5	9	9	4	12
Retired, n	1	12	11	6	15
On sick leave, n	2	3	10	3	12
Social status					
Married, n	8	—	—	—	—
Single, n	2	—	—	—	—
With small children or grandchildren, n	3	—	—	—	—

PM: polymyositis, DM: dermatomyositis, MCTD: mixed connective tissue disease, SSc: systemic sclerosis (scleroderma), CPK: creatine phosphokinase

questions. No patient suggested any additional activity. Thirty-seven questions with medians for difficulty/importance of 6.0 or higher were included in draft 2 of the MAP (Table 2).

Internal redundancy. Correlations between questions in the subscale Movement activities (n = 10) varied between r_s = 0.07 and 0.90, in Activities of moving around (n = 5) between r_s = 0.58 and 0.93, in Self-care activities (n = 10) between r_s = 0.48 and 0.91, in Domestic activities (n = 6) between r_s = 0.43 and 0.86, in Interpersonal activities (n = 3) between r_s = 0.22 and 0.92, and in Performing tasks and major life activities (n = 3) between r_s = 0.14 and 0.37. The 2 questions about walking stairs with/without handrails were redundant (r_s = 0.93): the former was removed as it was scored lower. The questions about washing hair and putting on a heavy coat or jacket were redundant (r_s = 0.91): the latter was removed as it was scored lower. The 2 questions about sex life were also redundant (r_s = 0.92). Further, answers, respectively, to these questions were missing from 7 and 8 patients, and so both were removed. Thus 33 activities, divided into 5 subscales and one single question, remained (Table 2).

Internal consistency. Correlations between the subscore for Movement activities and its 10 items varied between r_s = 0.20 and 0.91, for Activities of moving around and its 5 items between r_s = 0.62 and 0.75, for Self-care activities and its 10 items between r_s = 0.61 and 0.90, for Domestic activities and its 6 items between r_s = 0.65 and 0.78, and for Performing tasks and major life activities and its 3 items between r_s = 0.30 and 0.51. Altogether, 5 activities were excluded due to poor internal consistency: 2 from the subscale Movement activities and all 3 from the subscale Performing tasks and major life activities (Table 2). As the activities of the latter subscale had been considered important, they were removed from the subscale and listed as single questions. The activity that together with the questions about sex life comprised the subscale Interpersonal activities was also listed as a single question. Thus the third draft of the MAP consisted of 31 questions divided into 4 subscales and 4 single questions (Table 3). The subscores of the MAP are calculated as the median values of the single items within each subscale.

Construct validity. The total median of the MAP correlated moderately with the HAQ score (r_s = 0.70) and less with FI (r_s = 0.55), subjective global disease impact (r_s = 0.43), and CPK levels (r_s = 0.17). The correlations between MAP Movement activities and AIMS2 subscales Walking and bending were (r_s = 0.67), Arm function (r_s = 0.57), and Work (r_s = 0.68). The correlations between MAP Activities of moving around and AIMS2 Walking and bending were (r_s = 0.72) and with AIMS2 Work (r_s = 0.56). MAP Self-care activities correlated with AIMS2 Walking and bending (r_s = 0.54), Arm function (r_s = 0.56), and Work (r_s = 0.58), respectively. MAP Domestic activities correlated with AIMS2 Mobility (r_s = 0.54) and Walking and bending (r_s = 0.72), respectively, and MAP Social activity correlated with AIMS Tension (r_s = 0.51), and the correlation between the MAP Over-exertion and AIMS2 Work was r_s = 0.69. All other correlations between MAP subscales and AIMS2 subscales were < r_s = 0.50.

Test-retest reliability. Weighted kappa coefficients ranged from 0.56 to 0.76 for the 4 MAP subscales and from 0.65 to 0.77 for the 4 single items. No systematic differences between the 2 test occasions were recorded (Table 4).

Table 2. The 37 items that were kept from the first to the second MAP draft which scored 6.00 or greater when perceived difficulty and importance (rated by 10 strategically chosen patients) were pooled.

	Difficulty and Importance, Median (range), n = 10	Difficulty, Median (range) n = 10	Importance, Median (range), n = 10
ICIDH-2 Classification [7]			
3 Movement activities			
3101 Maintain squatting position during other activities[1]	6.50 (5.0–10.0)	9.50 (5.0–10.0)	4.50 (1.0–10.0)
3102 Maintain standing position during other activities	7.00 (1.5–10)	8.00 (1.0–10.0)	8.00 (7.0–10.0)
3308 Get in or out of front seat of car	6.25 (5.0–9.0)	2.50 (1.0–8.0)	10.00 (7.0–10.0)
3400 Pick up objects from floor to higher level	6.25 (2.5–9.0)	4.50 (1.0–8.0)	8.50 (2.0–10.0)
3403 Carry bag > 1 kg on shouders or back	6.00 (3.0–8.5)	3.50 (1.0–7.0)	9.00 (2.0–10.0)
3405 Put down full bags from desk or car to floor or ground	6.75 (4.5–10.0)	5.50 (1.0–10.0)	9.00 (4.0–10.0)
3408 Lift up child, pet, or object in arms	6.25 (1.0–10.0)	5.00 (1.0–10.0)	7.50 (1.0 –10.0)
3601 Grasp and hold objects, e.g., frying-pan or spanner	7.75 (4.5–9.5)	5.50 (1.0–9.0)	10.00 (7.0–10.0)
3608 Do or undo buttons in shirt or blouse[1]	6.25 (5.0–9.0)	3.50 (1.0–9.0)	10.00 (5.0–10.0)
3700 Open heavy doors, e.g., car door	6.75 (4.0–10.0)	4.50 (1.0–10.0)	9.00 (7.0–10.0)
4 Activities of moving around			
4101 Walk more than 1 km on flat ground	6.00 (5.0–10.0)	3.00 (1.0–10.0)	10.00 (7.0–10.0)
4201 Climb 15 steps of stair with rail [2]	6.50 (5.0–10.0)	4.00 (1.0–10.0)	9.50 (5.0–10.0)
4202 Run after bus or jog	6.75 (4.0–9.0)	9.50 (6.0–10.0)	4.50 (1.0–8.0)
4208 Climb 15 steps of stair without rail	6.75 (2.0–10.0)	7.50 (1.0–10.0)	8.00 (2.0–10.0)
4402 Use public transportation, buses, subway, trains	6.00 (2.0–8.5)	2.00 (1.0–10.0)	9.50 (3.0–10.0)
5 Self-care activities			
5100 Wash hair	6.75 (5.5–9.0)	3.50 (1.0–8.0)	10.00 (10.0–10.0)
5101 Bath in bathtub	6.50 (2.0–9.5)	3.50 (3.0–9.0)	7.50 (1.0–10.0)
5202 Comb hair or use hairdryer	6.00 (5.5–9.0)	2.50 (1.0–8.0)	10.00 (9.0–10.0)
5205 Cut or polish toenails	6.25 (5.0–9.0)	5.50 (1.0–9.0)	9.50 (5.0–10.0)
5208 Wash back	6.75 (5.0–10.0)	2.00 (1.0–7.0)	9.50 (5.0–10.0)
5308 Dry oneself after using lavatory	6.00 (5.5–8.5)	2.00 (1.0–7.0)	10.00 (10.0–10.0)
5500 Take on and off sweater	6.00 (5.0–9.0)	2.00 (1.0–8.0)	10.00 (8.0–10.0)
5501 Take on and off trousers or stockings	6.25 (4.5–9.5)	2.50 (1.0–9.0)	10.00 (8.0–10.0)
5508 Take on and off shoes or boots	6.50 (5.0–9.0)	3.00 (1.0–8.0)	10.00 (9.0–10.0)
5509 Take on and off outdoor clothes, e.g., coat or jacket[3]	6.00 (5.5–8.5)	2.00 (1.0–7.0)	10.00 (9.0–10.0)
6 Domestic activities			
6202 Transport everyday commodities	7.75 (5.5–10.0)	5.50 (1.0–10.0)	10.00 (8.0–10.0)
6308 Put away plates and glasses to higher level	6.00 (4.0–8.0)	4.00 (1.0–8.0)	8.00 (5.0–10.0)
6401 Mop floors	6.00 (2.5–8.5)	5.50 (1.0–10.))	6.50 (3.0–10.0)
6402 Vacuum cleaning	8.00 (2.0–9.5)	6.50 (1.0–10.0)	9.00 (2.0–10.0)
6501 Maintain dwelling and furnishing, e.g., washing windows or mowing lawn	6.25 (4.0–10.0)	7.50 (4.0–10.0)	7.00 (2.0–10.0)
6502 Maintain or clean domestic appliances, e.g., vacuum cleaner, oven, or other electrical equipment	7.00 (3.5–10.0)	7.00 (1.0–10.0)	7.00 (2.0–10.0)
7 Interpersonal activities			
7401 Keep in touch with close friends or relatives	7.25 (5.5–9.0)	5.50 (1.0–8.0)	10.00 (8.0–10.0)
7601 Have sexual intercourse[4]	6.00 (5.0–9.0)	7.00 (2.0–9.0)	9.00 (2.0–10.0)
7602 Maintain satisfactory sexual relations[4]	6.00 (5.0–10.0)	6.00 (2.0–9.0)	10.00 (1.0–10.0)
8 Performing tasks and major life activities			
8203 Avoid exertion during daily activities[5]	7.50 (4.5–10.0)	6.00 (1.0–10.0)	9.50 (5.0–10.0)
8404 Be able to cope with work, studies, and/or home work to satisfactory degree[5]	8.50 (6.0–10.0)	7.50 (3.0–10.0)	10.00 (6.0–10.0)
8558 Be able to do recreational activities of choice[5]	7.75 (5.0–10.0)	6.50 (4.0–10.0)	9.00 (6.0–10.0)

[1]=Excluded due to poor internal consistency, [2]= excluded due to redundancy with 4208, [3]= excluded due to redundancy with 5100, [4]=excluded for practical/ethical reasons, [5]=kept despite poor internal consistency.

DISCUSSION

The procedure applied in this study, with the use of an internationally recognized theoretical framework[7] and input from professionals and patients in creating an assessment tool like the MAP, likely results in high content validity. The differences between the ICF[8] and the version of the ICIDH-2 Beta-2 draft[7] used in this study would have resulted in somewhat changed organization of the MAP, but not its content.

It may seem surprising that common activities such as

Table 3. The third and final draft of the Myositis Activities Profile, with 31 activities divided into 4 subscales and 4 single questions.

Movement activities
1. Maintain standing position during other activities
2. Get in or out of front seat of car
3. Pick up objects from floor to higher level
4. Carry bag > 1 kg on shoulders or back
5. Put down full bags from desk or car to floor or ground
6. Lift up child, pet, or object in arms
7. Grasp and hold objects, e.g., frying pan or spanner
8. Open heavy doors, e.g., car door
Activities or moving around
1. Walk more than 1 km on flat ground
2. Run after bus or jog
3. Climb 15 steps of stair without rail
4. Use public transportation, buses, subway, trains
Self-care activities
1. Wash hair
2. Bath in bathtub
3. Comb hair or use hairdryer
4. Cut or polish toenails
5. Wash back
6. Dry oneself after using lavatory
7. Take on and off sweater
8. Take on and off trousers or stockings
9. Take on and off shoes or boots
Domestic activities
1. Transport everyday commodities
2. Put away plates and glasses to higher level
3. Mop floors
4. Vacuum cleaning
5. Maintain dwelling and furnishing, e.g., washing windows or mowing lawn
6. Maintain or clean domestic appliances, e.g., vacuum cleaner, oven, or other electrical equipment
Single questions
1. Keep in touch with close friends or relatives
2. Avoid exertion during daily activities
3. Be able to cope with work, studies, and/or home work to satisfactory degree
4. Be able to do recreational activities of choice

Table 4. Answers to the Myositis Activities Profile on 2 test occasions with a one week interval.

	Test, n = 17, Median (range)	Retest, n = 17, Median (range)	Weighted Kappa Coefficient, K_w	Sign Test, $p < 0.05$
Subscale				
Movement	2 (1–6)	1 (1–6)	0.76	0.69
Moving around	4 (1–6)	3 (1–7)	0.56	1.0
Self-care	1 (1–4)	1 (1–4)	0.75	0.63
Domestic activities	3 (1–5)	3 (1–6)	0.76	1.0
Single question				
Social activities	1 (1–5)	1 (1–4)	0.68	0.38
Avoid over exertion	4 (1–6)	3 (1–7)	0.65	0.13
Work	4 (1–7)	4 (1–7)	0.73	1.0
Leisure	5 (1–7)	4 (1–7)	0.77	1.0

sitting down and rising from a chair or brushing teeth were not rated highly enough by the patients to be included, while less frequent activities, such as maintaining or cleaning domestic appliances, were included. The ability to perform the latter type of activities was possibly experienced as more threatened and thus as more important for maintaining independence.

Our choice of cutoff points for inclusion of items in the

MAP might be questioned. However, as no defined values for cutoff exist, our decision was pragmatic and based upon a predetermined preference for the approximate number of questions to be included in the MAP. A lower cutoff point would have resulted in too lengthy a questionnaire, while a higher value for cutoff might have resulted in one too short to be sensitive. The final version of the MAP took about 10 minutes to complete.

The use of 2 scales, one for difficulty and one for importance, for rating of activities has been suggested previously[31]. This is an attractive procedure, leaving the decision on possible activity limitation to the individual rather than to any predefined norm, and was considered adequate for the selection of items for the MAP. However, double ratings result in statistical problems, first when calculating the median of 2 ratings for each question, then a further median value for single questions creating a subscale, and finally a third median for a group of participants. Questions were thus reformulated in the second draft to include both difficulty and importance of an activity in one question on how much trouble the activity caused in daily life. To ensure the participants' recognition of both importance and difficulty, written instructions defined that a rather easily performed important activity might be experienced as causing as much trouble as one that is very difficult but not often performed. A 7 grade scale was recommended by a statistical professional to be stable and yet sensitive.

Altogether 6 activities had high internal redundancy and 5 had poor internal consistency. Sexual activities were excluded for practical-ethical reasons. It has been reported by Fries, *et al* that this type of question may be experienced as too personal[17] and the high proportion of participants leaving these questions unanswered in our study seems to confirm this. All 3 activities in the subscale Performing tasks and major life activities, with poor internal consistency, were considered as important and they were all rated as median of 7.50–8.50 regarding difficulty and importance by the patients in sample 1. Their poor consistency might be due to the subscale consisting of only 3 questions, and if they had been excluded this aspect of daily living would not be represented at all in the MAP. The 2 activities with poor consistency in the subscale Movement activities were considered to be as important as the others, but were rated somewhat lower, median of 6.25–6.50. These items were deleted, as Movement activities were still well represented in the MAP.

The construct validity of the MAP, as a disease-specific instrument for the assessment of activity limitation in myositis, was supported by its moderate correlation with the HAQ, which also assesses a similar construct. Poorer correlation with other constructs such as disease activity assessed by CPK levels, impairment assessed by Functional Index in myositis, and general well being further supports this. Furthermore, the correlation between the MAP and the HAQ was not high enough to conclude that they are interchangeable.

Construct validity was also supported by several expected correlations between subscales of the MAP and corresponding subscales of the AIMS2. However, some findings may seem surprising. The self-care subscales correlated less than expected, possibly due to differences in information about assistance needed to perform activities. The AIMS2 Work correlated with many of the MAP subscales, probably because it is only to be answered by those who are working and thus systematically excludes individuals with high disease impact. The lack of correlation between the AIMS2 Work and the MAP question on work might be because the latter also includes schoolwork and work at home. The AIMS2 Walking and bending correlated to all MAP subscales and one single item, probably because walking and bending are included in many of the MAP activities. There is no obvious explanation for the correlation between the MAP Domestic activities and the AIMS2 Mobility other than that the single question related to transportation that is included in both. The subscales Social activities and Leisure activities of the MAP and the AIMS2 Social activity did not correlate well, possibly because of the problems of creating a valid Swedish translation of the latter[26]. The MAP item Avoiding over-exertion is unique and does not directly correspond to any of the AIMS2 subscales.

Excellent test-retest stability was recorded for the MAP. The patients were instructed to fill out all questionnaires at home, where most daily activities are usually performed, and also because the evening was considered the most stress-free time of day. Blood samples for analyses of CPK levels were taken the same day or within a week from the test occasion in 21 cases. In those cases when blood samples were taken within a month prior to or after the other assessments, the CPK levels had been stable for about 6 months and thus presumably did not influence the comparisons significantly. In all cases but one the second MAP was mailed back to the clinic about one week after the first.

Based on our results we suggest that the MAP is a valid and reliable method for assessing activity limitations among patients with PM and DM in both a clinical environment and for scientific purposes. Whether it is also a sensitive tool for the evaluation of treatment outcome remains to be investigated. As it has been developed and validated in Sweden, translation and cross-cultural adaptation will be needed before it can be used in other countries[32].

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