Item Weightings for the Systemic Lupus International Collaborating Clinics / American College of Rheumatology Disease Damage Index Using Rasch Analysis Do Not Lead to an Important Improvement

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ABSTRACT. ***Objective.*** To develop Systemic Lupus International Collaborating Clinics/American College of Rheumatology Disease Damage Index (SLICC/ACR-DI) item weightings that improve the ability of the measure to predict patient mortality in systemic lupus erythematosus (SLE).

Methods. Disease damage was measured for 738 patients followed at the University of Toronto Lupus Clinic since diagnosis. Using Rasch analysis, item weightings were determined and tested for their ability to predict death in a logistic regression model. Receiver operating characteristic (ROC) curves were produced to compare the original and weighted scales' ability to discriminate patients that died during the followup period from those who remained alive.

Results. The average SLICC/ACR-DI score per patient was 1.66. In total, 138 of the patients died during a mean followup of 9.2 years. A Rasch analysis derived weighting scheme using weighted domain scores (SLICC/ACR-DI-weighted) was the best weighted scale, with item reliability = 94%, model mean square infit = 1.01 (STD = 0.05); model mean square outfit = 0.99 (STD = 0.3), separation 4.08. The SLICC/ACR-DI-weighted was modestly better than the SLICC/ACR-DI in discriminating patients who died from those who remained alive. Using standardized scores for comparability, the SLICC/ACR-DI-weighted was better in predicting patient death than the unweighted SLICC/ACR-DI [OR_{death}(SLICC/ACR-DI-weighted) = 1.7 vs OR_{death}(SLICC-ACR-DI) = 1.4; $p < 0.005$]. ROC curve analysis supports that the SLICC/ACR-DI-weighted was somewhat superior to the SLICC/ACR-DI for predicting mortality.

Conclusion. In this test set, the SLICC/ACR-DI-weighted was modestly better in predicting death than the traditional unweighted SLICC/ACR-DI. However, the SLICC/ACR-DI-weighted is more difficult to apply and the weightings appear not to have provided a clinically relevant improvement of the SLICC-ACR-DI. (J Rheumatol 2003;30:292–7)

Key Indexing Terms:
SYSTEMIC LUPUS ERYTHEMATOSUS LUPUS DAMAGE
SLICC RASCH WEIGHTINGS

The Systemic Lupus International Collaborating Clinics/ American College of Rheumatology Disease Damage Index (SLICC/ACR-DI) is the only currently available validated measure of disease damage for adult or childhood onset systemic lupus erythematosus (SLE)[1,2]. A score of 1 identifies SLE patients that have one SLICC/ACR-DI item present for at least 6 months continuously.

Arithmetic manipulations using the total SLICC/ACR-DI may not be appropriate, because a certain SLICC/ACR-DI score may not necessarily characterize a group of patients with the same degree of *clinically relevant* damage. For instance, a score of 1 is given to a patient with a small, nonvision-compromising cataract but also to a patient with permanent neurological deficit due to transverse myelitis. Weighting the items differently, depending on clinical

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severity, might improve the clinical relevance of the overall score. In the past the development of item weightings was examined, but it was found that weights of the SLICC/ACR-DI items did not help to better predict patient outcome[2]. In addition, a recent multicenter retrospective study showed that the unweighted scores of SLICC/ACR-DI increase with disease duration and are correlated with patient mortality[3]. These findings suggest that either the wrong weighting approach was used, or that weights do not improve the SLICC/ACR-DI. We explored these possibilities further with the hope of improving the clinical relevance of the measure.

Rasch analysis is a psychometric approach[4] that has been used to assess and improve rheumatology scales by generating appropriate item weightings[5-8]. We investigated the use of Rasch analysis to see if we could improve the predictive ability of the SLICC/ACR-DI.

MATERIALS AND METHODS

Study data set. Patients who fulfilled at least 4 ACR classification criteria for SLE[9] and were followed at the University of Toronto Lupus Clinic were studied using information collected prospectively on damage, mortality, disease duration, and patient age at diagnosis. Only the last SLICC/ACR-DI score of each patient was used for the analysis.

Study instrument. The SLICC/ACR-DI is an unweighted scale; a score of 0 (range 0–47) is given to a patient without evidence of disease damage. Damage scored by the SLICC/ACR-DI is grouped into 12 different domains (maximal score per domain in parentheses): ocular (2), neuropsychiatric (6), renal (3), pulmonary (5), cardiovascular (6), peripheral vascular (4), gastrointestinal (7), musculoskeletal (7), and skin (3). Damage scores are also given for premature gonadal failure (1), diabetes mellitus (1), and malignancy (2).

Rasch modeling. Rasch modeling is one of the newer psychometric approaches to develop measures. In contrast to traditional psychometric methods, such as Likert-type scales, where a person's trait level is estimated by summing the responses to individual items of a scale[10], using Rasch analysis[4] a patient's trait level is not simply estimated by the raw scores of a scale. Instead, Rasch estimates are based on probability models and calibrated to a continuous, equal-interval scale ("ruler"). Using Rasch-derived scores, patients are ordered along a "ruler" on which higher scores indicate more and lower scores less of the trait being measured. In Rasch analysis, the probability that a patient will have a certain response is modeled as a function of 2 parameters, a patient parameter and a damage item parameter. The *patient parameter* (P_n) estimates how much a person has of a certain trait. The value P_n locates patients along an equal-interval "ruler." The item parameter (I_i) is the *item difficulty*, so-termed because Rasch models were initially employed in educational testing. The Rasch model posits the probability that a patient will have a certain degree of a trait as a function of the distance between the patient's trait level (P_n) and the location of the damage item (I_i) along the ruler. As the distance ($P_n - I_i$) gets larger, the probability the patient will have the trait increases[10]. In Rasch models, the distance ($P_n - I_i$) is expressed as the exponent of the base e. The measurement points of the ruler are located at equal distances and the distance between each measurement point is expressed in *logit units*. As an illustration, Figure 1 displays the position of 4 hypothetical patients and 5 items along a hypothetical damage scale. Patient 4 has the largest amount of damage. Item 5 is the most "difficult" item (i.e., item coding for the most severe damage) and it is located to the right on the ruler. Patients that are located on the ruler at the same point as the item would have an estimated (median) probability of 0.5 of having this type of damage. In the Rasch model this point is also referred to as the *Thurstone threshold*. The more to the right a patient is located from this threshold, the more likely it is that the patient has this type of damage. For example, Patient 5 has a very high likelihood of having the damage item 1, because Patient 5 is located far to the right of item 1. Patient 2, however, is located to the left of the threshold of item 5 and has therefore a low probability of endorsing item 5. Thurstone thresholds express in logit units the category thresholds for each item of the ruler[11].

There are different types of Rasch models. While basic dichotomous Rasch models can only assess items with 2 response categories, the so-called polytomous Rasch models define the probabilities of items with several response categories. An example is shown in Figure 2: An item of a hypothetical damage scale, such as avascular necrosis (AVN), can be: 1, absent (no AVN); or a patient may have 2, a single-site AVN; or even 3, AVN in multiple sites. In the hypothetical example (Figure 2) Patients 1 and 2 have a probability < 0.5 to have a single-site AVN, whereas Patient 3 has probability = 0.5 of having a single-site AVN. Patients 4 and 5 have a very high probability of having at least a single-site AVN and > 0.5 probability of having multiple AVN in multiple sites. Useful categories of items have *advancing Thurstone thresholds*, meaning that the threshold of the higher category of the item is always to the right of the threshold of the lower category. Advancing Thurstone thresholds are depicted in Figure 2.

When there is a *good fit* of the Rasch model, the observed responses correspond well with those predicted by the Rasch model. Two statistics summarize the degree of fit to the Rasch model, the "infit" and "outfit" statistics. The infit and outfit of each item is standardized to expected values of 1.0. Scales that fit the Rasch model assumptions well have *items* with infit and outfit values close to 1.0, and it has been suggested that infit and outfit of items should be within a range of 0.7–1.3[11]. The *model mean square* of the infit and outfit is a measure of overall model performance. Again, the ideal Rasch model has a standardized mean model infit and outfit of 1.0. It has been suggested that a good scale/'ruler' should have a model 'infit' and 'outfit' value between 0.8 – 1.2. It has also been suggested that the *item separation*, i.e., the distance between 2 adjacent Thurstone thresholds on the ruler, should be between 1.4 and 5 logit units. More details of this methods are available in a number of conceptually and mathematically simple and more complex texts[11,12].

Approach used to test item weightings that were derived by Rasch analysis. Patient death was used as a surrogate marker for disease damage, expecting that, as suggested[3,13], patients with high SLICC/ACR-DI scores should have a lower probability to survive compared to patients with low scores. The weightings of the SLICC/ACR-DI items determined by Rasch analysis were subsequently assessed for their usefulness to predict patient mortality using the following methods: (1) 2 × 2 tables and chi-square test; (2) receiver operating characteristic (ROC) curve analysis[14]; and (3) logistic regression using patient death as outcome variable and disease duration and patient disease damage score as predictors. Values of the SLICC/ACR-DI-weighted and the current SLICC/ACR-DI were normalized and their –2 log likelihood ratios were compared using chi-square test.

RESULTS

Study data set/patients. Data from 738 patients (673 females, 65 males) followed prospectively were included. The mean age at diagnosis was 33.1 years [range 8–83, standard deviation (SD) 13.8]. The mean disease duration was 11.8 years (range 0.5–48, SD 9.1). A total of 138 patients (18.7%) died during the followup time and 474 had a SLICC/ACR-DI score > 0.

Rasch modeling approach. Various Rasch modeling procedures were performed: SLICC/ACR-DI items were tested in (1) dichotomous models (e.g., AVN present/AVN absent); (2) polytomous models (e.g., AVN absent/single-site AVN/multiple AVN); (3) polytomous models using the sum

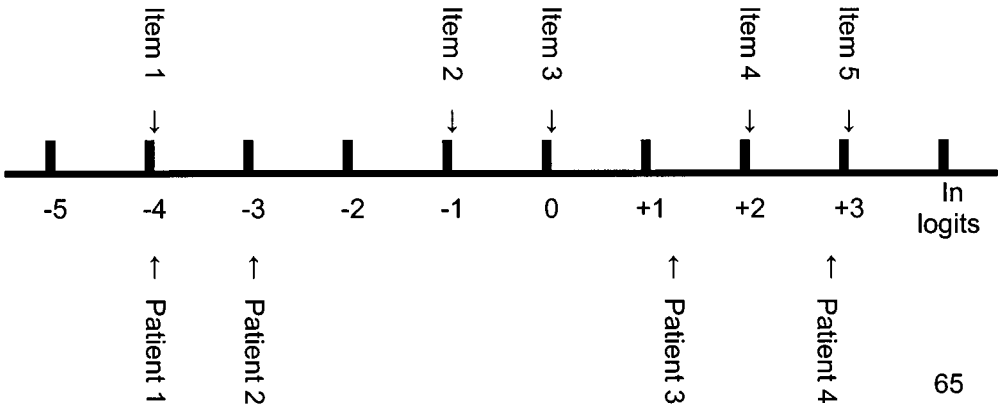

Figure 1. Hypothetical location in logits of 4 patients on a sample 5 item scale.

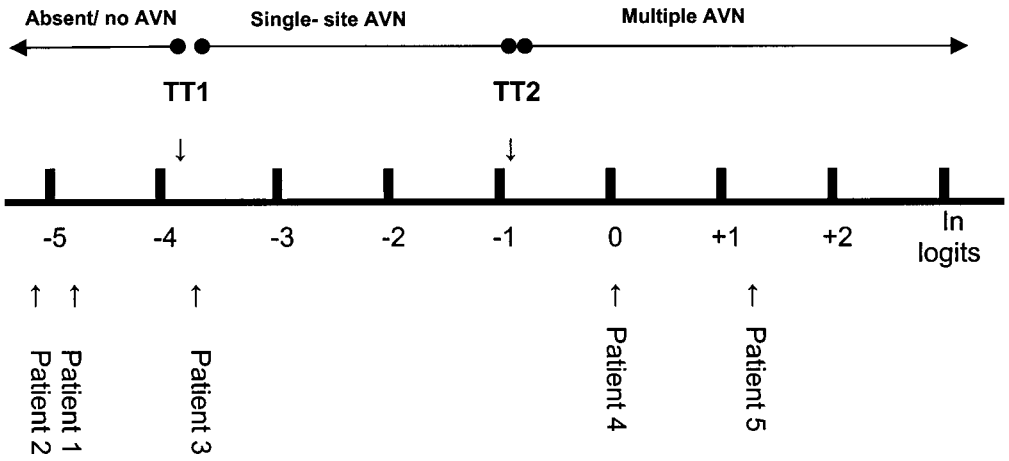

Figure 2. Hypothetical location in logits of 5 patients and Thurstone thresholds (TT) of a 3 category item using avascular necrosis (AVN) as an example.

of the domain scores (e.g., patient with cataract but no retinal disease has an ocular domain score of 1; patient with both cataracts and retinal disease has an ocular domain score of 2; patient with neither cataract nor retinal disease has an ocular domain score of 0). We also generated models using either the entire patient cohort (n = 738) or only the 474 patients with SLICC/ACR-DI scores > 0. All generated models were tested for the ability to predict patient mortality as described above.

The best Rasch model. Using this strategy, the best Rasch-derived item weightings were generated using the raw scores of the 12 SLICC/ACR-DI domains, considering only patients with damage for the calculation of item difficulties (SLICC/ACR-DI-weighted). This model had an item reliability (corresponds to Cronbach's alpha value) of 94%, mean model infit = 1.01 (SD 0.05), mean model outfit = 0.99 (SD 0.3). All 12 items, i.e., sums of the SLICC/ACR-DI domain scores, had item infits between 0.96 and 1.22 and item outfits between 0.79 and 1.24. The mean item separation was 4.08. Therefore, based on standard criteria[15], the SLICC/ACR-DI-weighted constitutes a good Rasch scale.

Comparison of SLICC/ACR-DI with SLICC/ACR-DI-weighted. The mean SLICC/ACR-DI score at the end of followup was 1.66 (range 0–12, SD 1.98, median 1) and 1330 SLICC/ACR-DI scores (items of damage) were recorded in the cohort. The mean score of the SLICC/ACR-DI-weighted was 6.5 (range 0–47.5, SD 7.56, median 35). The percentage distribution of the damage scores using the SLICC/ACR-DI and the SLICC/ACR-DI-weighted are shown in Table 1.

Sixty-four percent of the patients (474 of 738) had damage (SLICC/ACR-DI or SLICC/ACR-DI-weighted score > 0) (Table 2). Sixty-one of 138 patients (44.2%) died scoring below or at the median SLICC/ACR-DI score of 1 in the cohort. In contrast, only 41 of 138 (29.7%) patients who died scored below or at the median SLICC/ACR-DI-

Table 1. Comparison of the distribution of the SLICC/ACR-DI and SLICC/ACR-DI-weighted scores of the patients with disease damage (474 of 738 patients had SLICC/ACR-DI or SLICC/ACR-DI-weighted scores > 0).

Domain	Distribution of SLICC/ACR-DI Scores %	Distribution of SLICC/ACR-DI-weighted Scores %
Ocular	12	13
Neuropsychiatric	13	13
Renal	11	9
Pulmonary	3	6
Cardiovascular	11	10
Peripheral vascular	4	7
Gastrointestinal	4	6
Musculoskeletal	29	14
Skin	5	6
Premature gonadal failure	2	5
Diabetes	4	5
Malignancy	2	7
Total cohort score, %	100	100

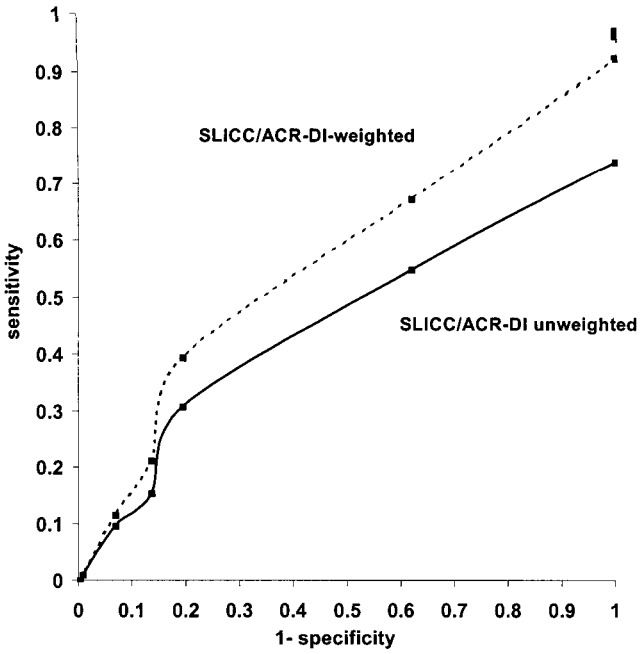

Figure 3. Receiver operating characteristic curve of SLICC/ACR-DI and SLICC/ACR-DI-weighted.

weighted score of 35. Therefore the SLICC/ACR-DI-weighted is superior to the SLICC/ACR-DI in discriminating patients that stayed alive from those that died [chi-square (DF 1) = 5.6, $p < 0.017$]. This is also supported by the results of the logistic regression, where patient death (outcome) was estimated by using the normalized damage scores (SLICC/ACR-DI, SLICC/ACR-DI-weighted) and disease duration as predictor variables. The SLICC/ACR-DI, but not disease duration, was a statistically important predictor of mortality (OR 1.38 for each standard deviation of increased damage, 95% confidence interval 1.27–1.69). Yet SLICC/ACR-DI-weighted scores were significantly better for predicting patient death (OR 1.70, 95% CI 1.34–2.15) than those of the SLICC/ACR-DI [chi-square (DF 1) of difference of –2 log likelihood values = 7, $p < 0.005$]. ROC curves confirmed that the SLICC/ACR-DI-weighted is better than the SLICC/ACR-DI in predicting patient death (Figure 3).

DISCUSSION

Rasch analysis was used to generate item weightings for the SLICC/ACR-DI. The weighted scale was statistically better for predicting death and discriminating patients that died from those that stayed alive. However, this difference in discriminatory performance was small. Although Rasch analysis provided item weightings that led to a somewhat higher ability to predict patient death, the differences were not marked, and the calculated item weightings are not very suitable for use in clinical practice in their current form.

There are several reasons why we might not have been successful in developing an improved SLICC/ACR-DI scale. First, Rasch analysis may not have been the optimal approach to develop item weightings, although this method has proven to be valuable for assessing and improving other outcome measures used in rheumatology[6,7,16,17].

Second, it may not be possible to improve the measurement properties of the SLICC/ACR-DI by developing item weightings. It has been suggested that item weightings rarely improve the properties of scales to a significant degree[18]. However, for other disease indices, such as the SLE Disease Activity Index (SLEDAI), item weightings were specifically incorporated in the scale development and were advantageous for the measurement properties of the SLEDAI[19]. In an exploratory analysis, item weightings derived that were similar to those used in the SLEDAI[19] were tested for their ability to predict patient death. This "SLEDAI-weighted" damage scale, however, did not predict patient death better than the current form of the SLICC/ACR-DI.

Third, the overall SLICC/ACR-DI summary score is not based on an ordinal scale, but has features of a nominal scale. While the items of an ordinal scale have a distinct inherent ranking order, this is not the case for nominal scales. For instance, it is not obvious whether damage coded in the cerebrovascular domain of the SLICC/ACR-DI or damage in its neuropsychiatric domain constitutes a higher degree of damage. Thus, patients with the same SLICC/ACR-DI score have only the same number of SLICC/ACR-DI damage items present, but they may not have the same degree of clinically relevant damage. For example, 2 patients with a SLICC/ACR-DI score of 1 each have one SLICC/ACR-DI damage item present. However, a wheelchair-bound patient after a single stroke, but also a

Table 2. Current SLICC/ACR-DI and SLICC/ACR-DI-weighted scoring schemes.

Domain Items	Unweighted Score			Domain Score	Weighted Score
1. Ocular					
Any cataract	0	1		1	3.5
Retinal changes OR optic atrophy	0	1		2	9.5
2. Neuropsychiatric					
Cognitive impairment or major psychosis	0	1		1	4
Seizures requiring therapy for 6 months	0	1		2	6
Cerebrovascular accident (CVA) (score 2 for > 1)	0	1	2	3	7.5
Cranial/peripheral neuropathy	0	1		4	10
Transverse myelitis	0	1		5	15
				6	20
3. Renal					
Estimated glomerular filtration rate < 50%	0	1		1	4.5
Proteinuria ≥ 3.5 grams/day	0	1		2	5.5
OR endstage renal failure (regardless of dialysis or transplantation)	3			3	7
4. Pulmonary					
Pulmonary hypertension	0	1		1	8
Pulmonary fibrosis	0	1		2	11
Shrinking lung	0	1		3	16
Pleural fibrosis	0	1		> 4	20
Pulmonary infarction OR resection not for malignancy	0	1			
5. Cardiovascular					
Angina OR coronary artery bypass grafting	0	1		1	4.5
Myocardial infarct (2 scores > 1)	0	1	2	2	5
Cardiomyopathy (ventricular dysfunction)	0	1		3	6
Valvular lesion (murmur)	0	1		4	7
Pericarditis × 6 months or pericardectomy	0	1		> 5	8.5
6. Peripheral vascular					
Claudication × 6 months	0	1		1	6.5
Venous embolism with swelling, ulceration OR venous stasis	0	1		2	8
Minor tissue loss (pulp space)	0	1		3	9
Significant tissue loss (score 2 if > 1)	0	1	2	> 4	11
7. Gastrointestinal					
Infarction OR resection of bowel, spleen, liver OR				1	7
Gallbladder (score 2 for > 1)	0	1	2	2	9
Mesenteric insufficiency	0	1		3	11
Chronic peritonitis	0	1		4	14
Stricture OR upper GI surgery ever	0	1		5	17
Pancreatic insufficiency (enzyme replacement or with pseudocyst)	0	1		6	20
8. Musculoskeletal					
Atrophy OR weakness	0	1		1	2
Deforming OR erosive arthritis	0	1		2	3
Osteoporosis with fracture OR vertebral collapse	0	1		3	5
Avascular necrosis (score 2 for > 1)	0	1	2	4	6
Osteomyelitis	0	1		5	7
Ruptured tendon	0	1		> 6	8
9. Skin					
Alopecia	0	1		1	7.5
Extensive scarring OR panniculum other than pulp space and scalp	0	1		2	11
Skin ulceration (excluding thrombosis) for more than 6 months	0	1		3	15
10. Premature gonadal failure	0	1		1	9.5
11. Diabetes (irrespective treatment)	0	1		1	7.5
12. Malignancy				1	9
Tumor (score 2 for > 1)	0	1	2	2	20

patient with a nonvision-compromising cataract will receive a score of 1, and the degree of clinically relevant damage is different between the 2 patients.

The Rasch analysis of the SLICC/ACR-DI supports (advancing Thurstone thresholds of item difficulties within each SLICC/ACR-DI domain; data not shown) that domain scores rather than the total SLICC/ACR-DI scores (i.e., the summation of all damage items included in all 12 domains)

should be used in statistical analyses of SLE damage, because SLICC/ACR-DI domain scores appear to have the properties of ordinal scales. To some extent this is considered in analyses where only the presence versus absence of damage as scored by the SLICC/ACR-DI in its relationship to prognostic or other clinical features is examined[13]. This strategy converts or collapses the SLICC/ACR-DI to a binary scale, making the absence of ordinal properties of the overall SLICC/ACR-DI scale irrelevant for the purpose of the analysis.

Finally, mortality as an external standard to validate item weightings is only one of many external proxies that could have been applied. Death of patients with SLE is multifactorial, not only the result of damage, and therefore other surrogates might have been more appropriate to validate suitable item weightings. Possibly patient quality of life or the intensity of medical interventions may be better external standards to develop relevant item weightings for the SLICC/ACR-DI that would improve the measurement characteristics of this scale. However, similar to the relationship between damage and patient death, the relationship between disease damage and quality of life is also influenced by many other factors[21] for which no retrospective information was consistently available. For example, we did not have information on treatment costs.

We do not support the use of Rasch weightings as developed by this study; however, an effort should continue to be made to develop a clinically relevant scoring scheme for disease damage in SLE.

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