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Assessment of severity of hand eczema: discrepancies between patient- and physician-rated scores

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Summary

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Key words

burden of disease, hand eczema, severity score

Conflicts of interest

None declared.

Background In clinical practice or trials on hand eczema the severity of this disease can be 'measured' in different ways: by means of a physician-rated clinical severity score, a patient-rated clinical severity score or by an indicator of the burden of disease. We assume that the patient-rated severity score corresponds more with the (change in) burden of disease than with the physician-rated severity score.

Objectives To demonstrate how physicians and patients differ in their assessment of the severity of hand eczema as seen in a physician-rated severity score, patient-rated severity score and a burden of disease questionnaire.

Methods We used data from an open-label randomized controlled trial which was set up in two university hospital dermatology departments in the Netherlands, specializing in hand eczema. One hundred and fifty-eight patients with moderate to severe chronic hand eczema were included. The main outcome measures were the physician-rated severity score, based on five visible aspects of hand eczema (desquamation, erythema, vesicles, infiltration, fissures), the patient-rated severity score (a self-rating scale), a burden of disease questionnaire (the Dermatology Life Quality Index, DLQI) and the correlations between these parameters, both at inclusion and over time.

Results Only desquamation and infiltration were significantly correlated with patient-rated severity score. Patient-rated severity score correlated with seven of 10 DLQI items, but it did not correlate with the items regarding influence on clothes worn, impairment of sporting activities, and problems associated with treatment of the skin. The majority of patients showed improvement in all parameters after treatment. However, the improvement in patient-rated severity score was not clearly correlated with changes in physician-rated severity score. Except for DLQI item 1 (itch, soreness, pain, stinging), none of the changes in burden of disease was correlated with changes in patient-rated severity score. For each DLQI item, change over time correlated weakly with decreases in several, but not all, components of the physician-rated severity score.

Conclusions Disease severity can be expressed by different scores; these scores are not clearly correlated, and measure different aspects. Patient satisfaction is not guaranteed when treatment is focused solely on the visible aspects of hand eczema. Instead, burden of disease has a greater impact.

We often 'measure' hand eczema for research and in clinical practice. This can be done with respect to its clinical severity and with respect to its impact on the patient's quality of life, or burden of disease. Both the physician and the patient may assess the severity of the hand eczema. The physician is limited to assessing the clinical severity, whereas the patient may also

indicate its consequences for specific aspects of life, which reflect his or her perception of the burden of the disease.

We will demonstrate how physicians and patients differ in their assessment of severity of hand eczema. In particular, we assume that the patient's assessment of the severity of hand eczema corresponds more with the (change in) consequences

of the disease in several aspects of life than with the physician's judgement.

The results will provide more insight into the discrepancies between the patient's and the physician's assessment of severity, as is so often encountered in daily practice. This may also help the physician to focus on those aspects of hand eczema that hinder the patient most, and help in explaining to the patient that medical therapy alone does not always alleviate all the consequences of hand eczema. Therefore, psychosocial counselling may also be necessary.

Patients and methods

Study population

The study was conducted within the framework of a randomized controlled trial which compared two types of psoralen plus ultraviolet A treatment.¹ The study population consisted of consecutive patients with chronic hand eczema attending two dermatology outpatient clinics. They were assessed for eligibility for inclusion into this trial. Inclusion criteria were: chronic bilateral or unilateral hand eczema of at least 1 year's duration, at least two relapses or more than three consecutive weeks with visible signs in the last 3 months, and a severity score of at least 6 (sum of scores of both hands), as rated by a dermatologist.² In total, 196 patients were considered to be eligible for this trial. Twenty-four patients did not meet the inclusion criteria, and 14 refused to participate. The remaining 158 patients gave written informed consent.

All patients were seen over a 10-week period. Assessments of severity and burden of disease were done at randomization (T1) and after the 10-week treatment period (T2).

Data collection

The severity of each patient's hand eczema was assessed by a dermatologist using a scoring system based on the following five visible aspects of hand eczema: erythema, desquamation, vesiculation, infiltration and fissures. This is a modification of

the severity score reported by Rosén *et al.*² Each item was scored as 0, 1, 2 or 3 for each hand separately (the higher the score, the more severe is the disease). The final severity score was calculated by averaging the scores of both hands and rounding to a whole number. Itch and pain, items included in the scoring system as described by Rosén *et al.*,² were not included because these cannot be assessed objectively by a physician. Changes in the physician-rated severity score were calculated by deducting the score at T1 from the score at T2, resulting in a negative number when there was improvement.

The patient's perception of the severity of the hand eczema (patient-rated severity score) was established with a self-rating scale from 1 to 10: 1 for very severe ('bad') and 10 for no signs and symptoms ('good'). This kind of rating is commonly used in the Netherlands, analogous to a report mark. Changes in the patient-rated severity score were calculated by deducting the score at T1 from the score at T2, resulting in a positive number when there was improvement.

As there is no questionnaire for specifically measuring the burden of the disease in patients with chronic hand eczema, we used the Dermatology Life Quality Index (DLQI).³ The DLQI consists of 10 questions on several different aspects of a patient's life that may be affected by a skin disease. We assumed that the DLQI would also cover essential aspects of hand eczema (see Table 1). Each item was scored as 0, 1, 2 or 3, where higher scores indicated more problems. Changes in the burden of disease were calculated by deducting the DLQI score at T1 from the score at T2, resulting in a negative number when there was improvement.

Statistical analysis

The mean and SD were calculated for all variables. As the physician-rated severity score and the DLQI items consist of only four categories, a distribution of frequencies at T1 is also shown.

The physician-rated severity score and DLQI items are considered to measure at an ordinal level. Therefore, the relationship between these items and the patient-rated severity score

Table 1 Dermatology Life Quality Index³

Item	Question
1	Over the last week, how itchy, sore, painful or stinging has your skin been?
2	Over the last week, how embarrassed or self-conscious have you been because of your skin?
3	Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?
4	Over the last week, how much has your skin influenced the clothes you wear?
5	Over the last week, how much has your skin affected any social or leisure activities?
6	Over the last week, how much has your skin made it difficult for you to do any sport?
7	Over the last week, has your skin prevented you from working or studying? If 'No', over the last week how much has your skin been a problem at work or studying?
8	Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?
9	Over the last week, how much has your skin caused any sexual difficulties?
10	Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?

Patients were instructed to give one answer for each question. They could choose from: very much, a lot, a little, not at all or not relevant.

is expressed by means of Spearman's rank correlations. Multi-variable methods were considered but, in the absence of known confounders, were deemed unhelpful.

To describe the change over time in the physician-rated severity scores and in the DLQI items in a meaningful way, the percentage of patients who improved is given, whereby only patients with a score > 0 at T1 are considered (i.e. only the patients who have a problem in connection with this specific item).

We calculated the Spearman's rank correlations between, respectively, the patient-rated severity scores, the physician-rated severity scores and the DLQI. We did the same for the changes over time for the severity parameters. A correlation of 0.10 is considered weak and 0.30 moderate. $P < 0.05$ was considered statistically significant.

Results

Physician-rated severity score and patient-rated severity score at randomization

During an 18-month period, 158 patients, 88 men (56%) and 70 women (44%) (mean \pm SD age 42 ± 14 years, range 18–70), were enrolled into this study.

At T1, desquamation and erythema were scored most frequently (in 99% of the patients) and had the highest scores of the five aspects of the physician-rated severity score (a mean of 1.9) (Table 2).

Only desquamation and infiltration were significantly correlated with the patient-rated severity score ($r = -0.20$). The mean patient-rated severity scores of the separate judgements by the physician are also shown in Table 2. Desquamation, erythema and infiltration showed a weak linear relationship between the physician-rated severity score and the patient-rated severity score.

Patients assessed the severity of their hand eczema with a mean \pm SD score of 4.4 ± 1.6 , which indicated much discontent (a lower score indicates more severe disease). Only 20% of the patients scored 6 or higher.

Burden of disease and patient-rated severity score at randomization

The mean \pm SD total DLQI score at T1 was 9.7 ± 6.6 . The items that revealed the highest impact on the burden of disease were DLQI items 1 and 3, measuring pain/itch and skin problems preventing shopping or looking after the home or garden (see Table 3).

With the exception of the items regarding the influence on clothes worn, impairment of sporting activities and problems associated with treatment of the skin (i.e. DLQI items 4, 6 and 10), all other DLQI items were significantly related to the patient-rated severity score. The highest correlations were noted for the items regarding itch/soreness/pain/stinging, going shopping or looking after the home or garden and impairment of work or study (DLQI items 1, 3 and 7). Especially those patients who rated the burden of disease on a particular aspect as 'very much' appeared to grade their disease as more severe, i.e. scored higher in the patient-rated severity scale.

Changes over time

A decrease in the severity and the burden of disease was to be expected because all patients were treated for their hand eczema between T1 and T2. Many patients did not have all the symptoms that were characteristic for hand eczema. Moreover, not all patients indicated their hand eczema to be a burden for all 10 different aspects of life. Therefore, when describing changes between T1 and T2, and the relationships between changes in indicators, we have chosen to describe the percentages of patients who had the possibility to improve their score and to describe the percentage of that group who did indeed improve their score (Tables 4 and 5). Of the 158 patients enrolled at the start (T1), 33 dropped out during the treatment period.

Most of the patients who had a particular problem as assessed by the physician (i.e. who had symptoms of desquamation, erythema, vesicles, infiltration or fissures) of showed

Table 2 Descriptives of components of the physician-rated severity score at randomization

	Mean	SD	0	1	2	3	Correlation ^a
Desquamation	1.9	0.7	1%	23%	62%	15%	-0.20*
Mean PRS			–	4.8	4.4	3.8	
Erythema	1.9	0.6	1%	23%	65%	11%	-0.10
Mean PRS			–	4.7	4.3	4.2	
Vesicles	0.6	0.8	54%	30%	15%	1%	0.10
Mean PRS			4.3	4.4	4.8	4.0	
Infiltration	0.9	0.7	28%	55%	15%	3%	-0.20*
Mean PRS			4.7	4.4	3.7	3.3	
Fissures	0.9	0.9	39%	36%	22%	3%	-0.09
Mean PRS			4.5	4.4	4.0	4.4	

PRS, patient-rated severity score. ^aCorrelation between patient-rated severity score and the corresponding aspect of the physician-rated score of hand eczema (Spearman's rank correlation). * $P < 0.05$.

Table 3 Descriptives of the Dermatology Life Quality Index (DLQI) at randomization

	Mean	SD	0	1	2	3	Correlation ^a
DLQI 1	2.1	0.9	5%	19%	42%	35%	-0.36*
Mean PRS			4.5	4.8	4.9	3.4	
DLQI 2	1.2	1.1	35%	30%	18%	18%	-0.27*
Mean PRS			4.8	4.5	4.0	3.5	
DLQI 3	1.6	1.1	22%	25%	29%	24%	-0.34*
Mean PRS			4.9	4.8	4.2	3.5	
DLQI 4	0.5	0.8	68%	18%	11%	3%	-0.11
Mean PRS			4.5	3.8	4.6	3.2	
DLQI 5	1.2	1.1	32%	30%	21%	17%	-0.23*
Mean PRS			4.6	4.9	3.9	3.4	
DLQI 6	0.9	1.2	56%	16%	11%	18%	-0.10
Mean PRS			4.5	4.9	4.3	3.7	
DLQI 7	0.7	1.1	67%	11%	7%	15%	-0.32*
Mean PRS			4.7	4.1	3.7	3.4	
DLQI 8	0.4	0.8	77%	12%	5%	6%	-0.21*
Mean PRS			4.5	4.5	2.7	3.3	
DLQI 9	0.5	0.9	75%	11%	9%	6%	-0.20*
Mean PRS			4.5	4.3	3.9	3.1	
DLQI 10	0.8	1.0	49%	26%	18%	6%	-0.03
Mean PRS			4.3	4.7	4.5	2.5	

PRS, patient-rated severity score. ^aCorrelation between patient-rated severity score and the corresponding DLQI item (Spearman's rank correlation). *P < 0.05.

Table 4 Changes in components of the physician-rated severity score and Spearman's rank correlations

Change in	Reporting complaints at T1 (%)	Of those, improvement at T2 (%)	Correlation with change in patient-rated severity
Desquamation	100	67	-0.13
Erythema	100	56	-0.06
Vesicles	45	69	0.04
Infiltration	74	67	-0.09
Fissures	59	78	-0.10

T1, at randomization; T2, after the 10-week treatment period. Number of patients = 123.

an improvement ranging from 56% for erythema to 78% for fissures (Table 4).

The total patient group rated the severity of their hand eczema (patient-rated severity score) a mean \pm SD of 1.1 ± 1.8 points higher at T2. This more positive judgement was, however, not related to the changes in the physician-rated severity score.

Of the patients who reported problems in various aspects of life caused by hand eczema (i.e. who scored 'a little'/'a lot'/'very much' on the DLQI items), the majority experienced improvement, ranging from 56% for itch and pain (DLQI item 1) to 77% among those who reported problems with treatment of their skin (DLQI item 10). With the exception of item 1 ($r = -0.22$), however, none of these changes in bur-

Table 5 Changes in the Dermatology Life Quality Index (DLQI) and Spearman's rank correlations

Change in	Reporting complaints at T1 (%)	Of those, improvement at T2 (%)	Correlation with change in patient-rated severity
DLQI 1	94	56	-0.22*
DLQI 2	65	70	-0.19
DLQI 3	79	66	-0.16
DLQI 4	33	71	0.16
DLQI 5	66	72	-0.04
DLQI 6	44	76	-0.00
DLQI 7	37	67	-0.06
DLQI 8	24	72	-0.04
DLQI 9	24	68	0.05
DLQI 10	51	77	-0.06

T1, at randomization; T2, after the 10-week treatment period. Number of patients = 107. *P = 0.029.

den of disease was significantly related to a change in patient-rated severity score (Table 5).

In Table 6 the relationships between changes in physician-rated severity score and changes in the burden of disease are presented. For each DLQI item, the change over time is correlated with a decrease in a component of the physician-rated severity score. Overall, both indicators are only weakly related. In fact, correlations of more than 0.40 were found only between a decrease in erythema and an improvement of pain/itch, and between a decrease in infiltration and a change in social or leisure activities.

Table 6 Relationship between changes in physician-rated severity score and the burden of disease

	Δ Desquamation	Δ Erythema	Δ Vesicles	Δ Infiltration	Δ Fissures
Δ DLQI 1	0.32*	0.48*	0.21*	0.33*	0.25*
Δ DLQI 2	0.30*	0.29*	0.25*	0.26*	0.20*
Δ DLQI 3	0.24*	0.29*	0.13	0.29*	0.24*
Δ DLQI 4	0.00	0.22*	0.09	0.08	0.02
Δ DLQI 5	0.28*	0.23*	0.22*	0.41*	0.16
Δ DLQI 6	0.22*	0.25*	0.20*	0.17	0.11
Δ DLQI 7	0.21*	0.08	0.15	0.32*	0.20*
Δ DLQI 8	0.08	0.11	0.15	0.17	0.21*
Δ DLQI 9	0.08	0.02	0.10	0.14	0.21*
Δ DLQI 10	0.14	0.05	0.19	0.251	0.10

DLQI, Dermatology Life Quality Index. *P < 0.05.

Discussion

Patients may indicate the burden of their disease for 10 different DLQI items. The mean DLQI was 9.7. Hutchings *et al.*⁴ reported an overview of mean DLQI scores for 15 dermatoses. Only urticaria with delayed pressure urticaria (DLQI 12.9) and atopic eczema (DLQI 12.5) had a higher mean score.^{5,6} Diseases such as psoriasis (8.9) and hair loss (8.3), which are well known for their burden of disease, had lower scores.^{3,7} This illustrates the high impact of hand eczema on the patient's well-being. It should, however, be kept in mind that our study did not include patients with mild hand eczema.

There was a weak relationship between physician-rated severity score and patient-rated severity score at T1. In general, an improvement in visible aspects of hand eczema did not lead to an improvement in the patient's assessment. Two different physician-rated severity scores have recently been validated; unfortunately, these instruments were not yet available at the time of our study.^{8,9}

We noted a weak to moderate relationship between patient-rated severity score and the burden of disease; however, a correlation coefficient of 0.36 (such as between DLQI item 1 and patient-rated severity) implies that only 13% of the variability can be explained by the correlation. An improvement in the burden of disease did not correspond to an improvement in patient-rated severity score.

Finally, an improvement in physician-rated severity score was weakly to moderately related to improvement in the burden of disease. This relationship was more pronounced for erythema with itch/soreness/pain (DLQI item 1), and for infiltration with social/leisure activities (DLQI item 5), although the correlation explains only up to 23% of the variability.

The high drop-out rate of 21% may be considered a potential source of bias. There was, however, no difference between the drop-outs and the remaining participants with regard to physician-rated severity score at T1 or change between T1 and T2.¹ Furthermore, the physician-rated severity score was calculated by taking the mean score of the right and the left hand. Thus, the most severely affected or dominant hand was not taken into account.

We asked ourselves to what extent the DLQI measured problems that were solely attributable to hand eczema, a question that may also be posed for burden of disease questionnaires other than the DLQI. To date, only the DLQI has been validated for patients with hand eczema.¹⁰

Our findings are similar to those of Jayaprakasam *et al.*,¹¹ who reported that the interpretation of burden of disease from disease severity is unreliable. They had, however, only looked at physician-rated severity and not at patient-rated severity. In addition, the study was not limited to hand eczema, or to another specific skin disease. Heydendaal *et al.*¹² also reported no significant relationship between disease severity and burden of disease.

Cvetkovski *et al.*¹³ described how the patients' self-assessment of their hand eczema was significantly more severe than the dermatologist's rating, who used a standardized severity assessment tool. This resulted in a very low positive predictive value and a high negative predictive value of the patient's self-assessment. This limited relationship between patients' and physicians' opinions is in line with our own findings. The same authors report a DLQI of 5.5 among hand eczema patients in a paper that examines a link between depression and the separate DLQI items; their lower mean score compared with ours may be explained by the fact that almost a third had minimal severity.¹⁴

These findings are important to the dermatologist. When treatment is focused solely on the visible aspects of hand eczema, patients' satisfaction with their skin condition is not guaranteed. Alleviation of burden of disease has a higher impact on patients' assessment of their hand eczema. Although medical treatment of some visible aspects of chronic hand eczema has to some extent an impact on the burden of disease, patients may also need counselling and support by other professionals such as, for example, specialized nurses, to cope with their disease.

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