

## CLINICAL REPORT

# Reliability, Responsiveness and Validity of Scalpdex in Children with Scalp Psoriasis: The Dutch Study

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**This aim of this study was to validate the Scalpdex, a quality of life questionnaire for adults with scalp dermatitis, in children with scalp psoriasis. The reliability, responsiveness and validity of the 3 scales (symptoms, functioning and emotions) of this 22-item questionnaire were analysed in a cohort of children with scalp psoriasis (age range 6–18 years). A total of 94 children completed the questionnaire once, and 53 children a second time, after treatment of their scalp psoriasis. The Children's Scalpdex in Psoriasis (CSP) demonstrated reliability with internal consistency (Cronbach's  $\alpha$ , 0.69–0.91). The CSP scales proved sensitive to change in the expected direction for children whose scalp psoriasis improved. Moderate effect sizes were observed between both visits for all 3 scales of the CSP (Cohen's  $d$ , 0.44–0.58). In conclusion, the CSP is a reliable, responsive and valid questionnaire, which is the first to illustrate the specific influence of scalp psoriasis on quality of life in children. Key words: scalp psoriasis; children; questionnaire; quality of life assessment.**

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In children, the scalp is a predilection site for psoriasis, and studies have demonstrated that the scalp is most often the initial site affected (1–4). Scalp involvement is reported in 47.0–88.9% of all children with psoriasis (5–8). Involvement of the scalp can be a particular burden for patients with psoriasis because of the visibility of the lesions, and it is difficult to apply therapy (9). Chen et al. (10) developed and validated the Scalpdex, a quality of life (QoL) questionnaire specifically for adults with scalp dermatitis (psoriasis and seborrhoeic dermatitis). This instrument can be used to determine which aspect of scalp dermatitis bothers patients the most, and to evaluate the influence of therapeutic intervention on QoL.

The impact of scalp psoriasis on QoL, especially in children with psoriasis, has not been investigated. Although a skin-specific questionnaire exists to measure QoL in children with skin diseases of the whole body (Children's Dermatology Life Quality Index, CDLQI) (11), there is no specific instrument to assess the influence of scalp psoriasis on QoL in children.

This study aims to validate the Scalpdex in children with scalp psoriasis. The Children's Scalpdex in Psoriasis (CSP) was assessed for its reliability, responsiveness and validity. The validation of an additional QoL questionnaire for children with scalp psoriasis will make it possible to focus on the symptoms and emotional and psychological impact of scalp psoriasis in children and to assess the influence of treatments.

## MATERIALS AND METHODS

### *Instrument development*

The content of the CSP questions was based on the validated Scalpdex questionnaire (10). The Scalpdex was developed based on focus sessions with adult patients with scalp psoriasis and seborrhoeic dermatitis. Fourteen scalp dermatitis-specific items were formulated from these in-depth interviews, and 9 items from the Skindex were included (12). The questionnaire comprised 23 items, which were clustered and tested by factor analyses into 3 scales, labelled "symptoms", "functioning" and "emotions".

For the CSP, the Scalpdex items were translated into Dutch and discussed in a steering group, comprising 2 dermatologists, 1 paediatric dermatologist and one psychologist with a broad expertise in questionnaires for children with psoriasis. When necessary, the questions were modified slightly in order to make them more comprehensive for children. The item; "The cost of caring for my scalp condition bothers me", was not included, because the steering group agreed that children are unlikely to be concerned about this topic. The CSP thus comprises 22 items, which consist of 3 major constructs, "symptoms", "functioning" and "emotions", which is in line with the original Scalpdex. All items enquired about the past 4 weeks. Responses to the questions were based on a 5-point Likert-type scale ("never" = 0, "rarely" = 25, "sometimes" = 50, "often" = 75, and "all the time" = 100). A lower score represents a better QoL. The responses to item 19, "I feel that my knowledge about caring for my scalp psoriasis is adequate", were reverse scored. Scale scores were the mean of responses to items in a given scale. If necessary, patients aged between 6 and 12 years were allowed

to complete the questionnaire with the help of the child's parent or guardian. The CSP takes 5–10 min to complete.

### Sample population

The department of dermatology of Radboud University Nijmegen Medical Centre has a prospective observational juvenile psoriasis cohort (<18 years) from daily clinical practice, called the Child-CAPTURE (Continuous Assessment of Psoriasis Treatment Use Registry). All of the children aged between 6 and 18 years who visited the department between March 2011 and May 2012 with more than 5% scalp area involvement completed the questionnaire at baseline. Patients were treated for their scalp psoriasis according to the physician's opinion. The following patient characteristics were recorded: age, gender, age at onset, family history and duration of psoriasis.

### Outcome measures

At baseline, and if applicable at a second visit, the 22 items of the CSP were completed (range 0–100). In addition, patient's QoL was evaluated with the validated Dutch version of the Children's Dermatology Life Quality Index, CDLQI (10 items; range 0–30) (11, 13). For both questionnaires, higher scores indicate worse QoL. It is hypothesized that the CSP is better than the CDLQI questionnaire to assess the explicit impact of scalp psoriasis on QoL in children. Severity of scalp psoriasis was established by the Physician Global Assessment of the Scalp (PhGA scalp; range 0–5) and Patient Global Assessment of the Scalp (PaGA scalp; range 0–5). Clinical severity of psoriasis of the whole body was assessed by a clinician using the Psoriasis Area and Severity Index (PASI; range 0–72) (14).

### Statistical analyses

The CSP was tested for reliability, responsiveness and validity. Reliability was assessed by Cronbach's  $\alpha$  at scale level. This expresses internal consistency; whether the items in the scale are correlated, and thus are measuring the same concept. A Cronbach's  $\alpha$  coefficient  $\geq 0.70$  is considered acceptable (15). For construct validity, first confirmatory factor analysis was performed to test whether the 3 constructs of the Scalpdx (symptoms, functioning and emotions) are similar in the CSP. Thereafter, the correlations between the mean scale scores of the CSP and the CDLQI and the scalp psoriasis severity scores by patient and physician were examined using Spearman's rank correlation coefficient. It was hypothesized that CSP would be positively correlated with all the different scalp psoriasis severity scores and have higher correlations than the CDLQI with the scalp severity scores. For the discriminant validity, we hypothesized that the CDLQI, a skin-specific questionnaire for the whole body, is not sensitive enough to measure responsiveness over time for changes in the QoL specific to scalp psoriasis. Cohen's D was calculated for responsiveness of both the CSP and the CDLQI. Responsiveness of the CSP and CDLQI questionnaires was tested by calculating the change in the mean scale scores (symptoms, functioning and emotions) of the CSP and the change in total CDLQI of the patients who completed the questionnaire twice. Cohen's D was used to calculate within-group effect sizes, to indicate the standardized differences between 2 means at the 2 occasions, before and after treatment of the scalp psoriasis, for both the CSP and the CDLQI. Cohen's d is defined as the difference between 2 means, divided by the standard deviation (SD). A Cohen's D of 0.2 was considered to indicate a small effect, 0.5 to indicate a medium effect, and effects higher than 0.8 to indicate large effects (16). The paired *t*-test was applied to the baseline answers and the answers of the second time-point for 3 groups: those who improved according to the opinion of

the physician (PhGA scalp) or their own opinion (PaGA scalp); those who showed no change in their scalp psoriasis, and those whose scalp conditioned worsened. Statistical analyses were performed in SPSS software 18.0 (SPSS Inc., Chicago, IL, USA) and Mplus version 6.11.

## RESULTS

### Study sample

Patient characteristics of the study cohort are shown in Table I. A total of 94 children, mean age  $12.4 \pm 3.3$  years, with scalp psoriasis completed the questionnaire once. The majority of patients were female (59.6%). Patients had a mean duration of psoriasis of  $3.7 \pm 3.5$  years and a mean psoriasis severity (PASI) of  $4.8 \pm 2.8$ . Both patients (PaGA scalp) and physician (PhGA scalp) reported a median scalp psoriasis severity of 2 (range 1–5). Fifty-three patients completed the questionnaire a second time.

### Item analysis

Mean  $\pm$ SD item scores of the CSP demonstrated that the following 3 items were most affected (Table II): "I am bothered by the persistence/reoccurrence of my scalp psoriasis" ( $55.3 \pm 33.4$ ), "My scalp psoriasis itches" ( $52.9 \pm 31.5$ ) and "I feel that my knowledge about caring for my scalp psoriasis is adequate" ( $51.9 \pm 34.0$ ). The item with the lowest mean score was the question: "My scalp psoriasis affects the colour of clothes I wear" ( $9.8 \pm 20.2$ ). In Table II the mean scores of all items are listed. In 8 out of 22 CSP items (36.4%) vs. 8 out of 10 CDLQI items (80%), at least 50% of the patients answered never.

### Reliability

Internal consistency reliability of the 3 scales was analysed with Cronbach's  $\alpha$ . For all the 3 scales the internal consistency was relatively high ("symptoms" = 0.69; "functioning" = 0.74, "emotions" = 0.91).

### Construct validity

Confirmatory factor analysis demonstrated an acceptable fit for the 3-factor model. This indicates that the

Table I. Patient characteristics (n=94)

Variables	
Age, years, mean $\pm$ SD (range)	12.4 $\pm$ 3.3 (6–17)
Gender, boys/girls, n (%)	38/56 (40.4/59.6)
Psoriasis history mean $\pm$ SD (range)	
Age at onset, years	8.3 $\pm$ 4.2 (0–17)
Duration of psoriasis, years	3.7 $\pm$ 3.5 (0–13)
Psoriasis baseline assessments scores	
PASI, mean $\pm$ SD	4.8 $\pm$ 2.8
Physician Global Assessment Scalp, median (range)	2 (1–5)
Patient Global Assessment Scalp, median (range)	2 (1–5)

Table II. Mean score of the items of the Children's Scalpdx in Psoriasis (n = 94)

Item	Scale <sup>a</sup>	Score <sup>b</sup>
		Mean ± SD
1. My scalp psoriasis hurts	S	23.9 ± 26.7
2. My scalp psoriasis makes me feel sad	E	23.1 ± 27.5
3. My scalp psoriasis itches	S	52.9 ± 31.5 <sup>c</sup>
4. I am ashamed of my scalp psoriasis	E	28.2 ± 31.2
5. I am embarrassed by my scalp psoriasis	E	14.9 ± 23.6
6. I am angry/frustrated by my scalp psoriasis	E	28.5 ± 29.6
7. I am humiliated by my scalp psoriasis	E	13.8 ± 23.7
8. My scalp psoriasis bleeds	S	26.1 ± 26.9
9. I am annoyed by my scalp psoriasis	E	43.1 ± 36.7
10. I am bothered by the appearance of my scalp psoriasis	E	31.4 ± 32.8
11. My scalp psoriasis makes me feel self-conscious	E	17.3 ± 24.6
12. I am bothered that my scalp psoriasis is incurable	E	41.5 ± 35.3
13. My scalp psoriasis affects how to wear my hair (hairstyle, hats)	F	20.7 ± 31.2
14. I am bothered by people's questions about my scalp psoriasis	E	34.0 ± 30.2
15. My scalp psoriasis affects the colour of clothes I wear	F	9.8 ± 20.2
16. I am bothered by the persistence/reoccurrence of my scalp psoriasis	E	55.3 ± 33.4 <sup>c</sup>
17. I feel stressed about my scalp psoriasis	E	12.8 ± 21.0
18. Caring for my scalp psoriasis is inconvenient for me	F	39.9 ± 34.8
19. I feel that my knowledge about caring for my scalp psoriasis is adequate	E	51.9 ± 34.0 <sup>c</sup>
20. My scalp psoriasis makes my daily life difficult	F	20.5 ± 25.4
21. My scalp psoriasis makes me feel different from others	E	22.6 ± 28.4
22. My scalp condition makes it hard to go to the hairdresser	F	22.3 ± 32.7

<sup>a</sup>Scales: symptoms (S), emotions (E) and functioning (F). <sup>b</sup>Item scores: 0 "never", 25 "rarely", 50 "sometimes", 75 "often" and 100 "all the time". <sup>c</sup>Three items with the highest mean scores.

3 scales of the Scalpdx (symptoms, functioning and emotions) can also be used in our CSP. Correlations were calculated between the scale scores of the CSP and the scores of scalp psoriasis severity, PhGA and PaGA (Table III). The highest significant positive correlations for all scales were demonstrated between PaGA scalp and the 3 scales; symptoms  $r=0.51$  ( $p<0.001$ ), functioning  $r=0.46$  ( $p<0.001$ ) and emotions  $r=0.46$  ( $p<0.001$ ). PhGA scalp also showed significant positive correlations with the 3 scales; symptoms  $r=0.44$  ( $p<0.001$ ), functioning  $r=0.32$  ( $p=0.002$ ), and emotions  $r=0.27$  ( $p=0.009$ ). The CDLQI correlated less significantly positively with both PhGA scalp ( $r=0.21$ ;

Table III. Correlations ( $r$ ) between scalp psoriasis severity scores and Children's Dermatology Life Quality Index (CDLQI) and the Children's in Scalpdx Psoriasis scales

	Children's Scalpdx in Psoriasis scales			
	Symptoms	Functioning	Emotions	CDLQI
PhGA	0.44**	0.32**	0.27**	0.21*
PaGA	0.51**	0.46**	0.46**	0.30**

\* $p<0.05$ ; \*\* $p<0.01$ .

PhGA: Physician Global Assessment; PaGA: Patient Global Assessment.

$p=0.05$ ) and PaGA scalp ( $r=0.30$ ;  $p=0.004$ ) compared with the CSP scales.

### Responsiveness and discriminant validity

A total of 53 patients completed the questionnaire a second time and were analysed for responsiveness. Because patients were seen in daily clinical practice, the period of time between the first and second visit varied between 1 and 7 months (mean ± SD;  $4.3 \pm 1.8$ ). First, effect sizes with Cohen's D were calculated between the 2 time-points for both CSP and CDLQI. Cohen's D for CSP showed moderate effect sizes (symptoms=0.44; functioning=0.58 and emotions=0.51), whereas no effect size was found for the CDLQI (Cohen's D=-0.03).

To evaluate the responsiveness of the CSP and the CDLQI with respect to changes in severity of scalp psoriasis, patients were divided into 3 groups. The first group consisted of patient with a worsening of their scalp psoriasis, either according to the physician (Table IV), or according to the patient's own opinion (Table V). The second and third group reported no change in severity or an improvement in their scalp psoriasis, respectively. Significant changes in all 3 scales of the CSP were found in the group with an improvement in their scalp psoriasis ( $p \leq 0.001$ ). This effect was found in improvements based on both PhGA and PaGA with a moderate size effect, Cohen's D between 0.66 and 0.98. Patients with worsening of the scalp condition based on alterations in PhGA scalp showed a significant increase in mean score for the scale "symptoms" ( $14.6 \pm 13.8$ ;  $p=0.004$ ), but not for the other 2 scales. It is notable that patients with the same scalp condition at both visits based on PhGA scalp showed a significant improvement for the emotions scale ( $-9.3 \pm 11.0$ ). All other alterations in both PaGA and PhGA scalp and the other scales demonstrated no significant increase or decrease in mean scores.

Interestingly, for patients in whom scalp psoriasis improved from both the physician and the patient's point of view (Tables IV and V) the skin-specific CLDQI questionnaire showed a significant increase in mean total CDLQI score (more impairment in QoL) (Table IV,  $n=26$ , PhGA scalp:  $\Delta$ CDLQI  $3.3 \pm 5.1$ ,  $p=0.03$ ; Table V,  $n=27$ , PaGA scalp:  $\Delta$ CDLQI  $2.5 \pm 5.7$ ,  $p=0.03$ ). Because of this, we analysed the course of psoriasis severity on other parts of the body for the patients in whom the scalp psoriasis improved. Surprisingly, the psoriasis severity of the entire body, expressed by the PASI, increased in this group (PhGA scalp:  $\Delta$ PASI  $3.1 \pm 4.2$ ,  $p=0.001$ ; PaGA scalp:  $\Delta$ PASI  $3.2 \pm 4.7$ ,  $p=0.001$ ), whilst the scalp psoriasis improved.

## DISCUSSION

The results of this study show that the CSP is a reliable, responsive and valid questionnaire. It is the first

Table IV. Mean scale scores for Children's Scalpdex in Psoriasis and Children's Dermatology Life Quality Index based on alterations in Physician Global Assessment of the scalp

Scalp condition	Scale	Scores, mean $\pm$ standard deviation		$\Delta$ (SD)	<i>p</i> -value	Cohen's D
		Visit 1	Visit 2			
Children's Scalpdex in Psoriasis						
Worse ( <i>n</i> =12)	Symptoms	22.9 $\pm$ 25.4	37.5 $\pm$ 21.5	14.6 (13.8)	<b>0.004</b>	-0.62
	Functioning	16.2 $\pm$ 22.4	19.6 $\pm$ 20.7	3.4 (11.5)	0.34	-0.16
	Emotions	27.4 $\pm$ 22.2	37.1 $\pm$ 27.4	9.7 (17.2)	0.08	-0.39
Same ( <i>n</i> =15)	Symptoms	30.6 $\pm$ 26.7	23.9 $\pm$ 22.5	-6.7 (22.3)	0.27	0.27
	Functioning	17.0 $\pm$ 17.7	13.0 $\pm$ 13.9	-4.0 (11.8)	0.21	0.25
	Emotions	24.5 $\pm$ 19.7	15.2 $\pm$ 16.0	-9.3 (11.0)	<b>0.006</b>	0.52
Better ( <i>n</i> =26)	Symptoms	35.9 $\pm$ 17.1	19.9 $\pm$ 15.5	-16.0 (19.3)	<b>&lt;0.001</b>	0.98
	Functioning	20.4 $\pm$ 15.4	8.7 $\pm$ 10.3	-11.7 (13.4)	<b>&lt;0.001</b>	0.89
	Emotions	24.9 $\pm$ 16.0	14.5 $\pm$ 14.6	-10.4 (14.0)	<b>0.001</b>	0.68
Children's Dermatology Life Quality Index						
Worse ( <i>n</i> =12)	-	5.5 $\pm$ 5.6	6.8 $\pm$ 3.9	1.3 (4.8)	0.36	-0.26
Same ( <i>n</i> =15)	-	5.0 $\pm$ 5.3	5.4 $\pm$ 4.3	0.4 (4.4)	0.29	-0.08
Better ( <i>n</i> =26)	-	3.5 $\pm$ 3.4	6.8 $\pm$ 4.6	3.3 (5.1)	<b>0.03</b>	-0.82

Significant *p*-values are shown in bold.

instrument to focus on scalp psoriasis in children, illustrating the specific influence of scalp psoriasis on QoL. This QoL questionnaire makes it possible to assess the symptoms and emotional and psychological impact of paediatric scalp psoriasis. For this group of children, the development of this questionnaire is important for clinical research, decision-making and evaluation of therapeutic interventions. In this study the questionnaire was validated for children with scalp psoriasis. However, it is highly likely that this questionnaire can also be used for other paediatric scalp conditions.

This study was performed in a juvenile psoriasis cohort, drawn from daily clinical practice, called the Child-CAPTURE (Continuous Assessment of Psoriasis Treatment Use Registry). This registry was set up in 2008 and aims to record clinical and QoL data from children with psoriasis every time they visit our outpatient clinic. For this study there was no wash-out period, and all patients were treated for psoriasis according to

the physician's opinion. Therefore, psoriasis severity at baseline of the study was mild.

In our cohort of children with scalp psoriasis the items "my scalp itches" and "I am bothered by the persistence/reoccurrence of my scalp condition" are the 2 items with the highest scores. This is in line with the original Scalpdex, in which Chen et al. (10) also demonstrated that adults with scalp dermatitis (psoriasis and seborrhoeic dermatitis) reported most problems with these items. In contrast to adults, however, children report more bleeding of the scalp, and are more troubled by people's questions about their scalp psoriasis. On the other hand, the children are less embarrassed and frustrated by their scalp psoriasis than adults are by their scalp condition and the children feel that their knowledge about caring for scalp psoriasis is adequate, more so than the adults. The reliability of the CSP scales was relatively high (Cronbach's  $\alpha$  0.69–0.91), and slightly better than the reliability reported by Chen et al. (10) for the Scalpdex (Cronbach's  $\alpha$  0.62–0.80).

Table V. Mean scale scores for Children's Scalpdex in Psoriasis and Children's Dermatology Life Quality Index based on alterations in Patient Global Assessment of the scalp

Scalp condition	Scale	Scores, mean $\pm$ standard deviation		$\Delta$ (SD)	<i>p</i> -value	Cohen's D
		Visit 1	Visit 2			
Children's Scalpdex in Psoriasis						
Worse ( <i>n</i> =10)	Symptoms	21.7 $\pm$ 26.7	31.7 $\pm$ 20.0	10.0 (18.3)	0.12	-0.42
	Functioning	13.5 $\pm$ 23.6	12.5 $\pm$ 19.8	-1.0 (7.7)	0.69	0.05
	Emotions	21.1 $\pm$ 22.3	26.3 $\pm$ 27.8	5.2 (16.1)	0.34	-0.21
Same ( <i>n</i> =16)	Symptoms	29.7 $\pm$ 19.7	31.3 $\pm$ 25.0	1.6 (16.7)	0.71	-0.07
	Functioning	17.8 $\pm$ 16.9	16.6 $\pm$ 14.9	-1.2 (15.9)	0.76	0.08
	Emotions	25.0 $\pm$ 16.2	23.2 $\pm$ 19.8	-1.8 (13.2)	0.60	0.10
Better ( <i>n</i> =27)	Symptoms	36.1 $\pm$ 21.4	18.8 $\pm$ 14.7	-17.3 (21.4)	<b>&lt;0.001</b>	0.94
	Functioning	20.7 $\pm$ 15.6	9.8 $\pm$ 12.0	-10.9 (1.8)	<b>&lt;0.001</b>	0.78
	Emotions	27.1 $\pm$ 18.3	15.4 $\pm$ 17.3	-11.7 (15.3)	<b>0.001</b>	0.66
Children's Dermatology Life Quality Index						
Worse ( <i>n</i> =10)	-	3.6 $\pm$ 4.6	5.8 $\pm$ 4.1	2.2 (4.3)	0.14	-0.50
Same ( <i>n</i> =16)	-	5.3 $\pm$ 4.0	6.3 $\pm$ 4.3	1.1 (3.9)	0.29	-0.24
Better ( <i>n</i> =27)	-	4.2 $\pm$ 4.8	6.7 $\pm$ 4.5	2.5 (5.7)	<b>0.03</b>	-0.54

Significant *p*-values are shown in bold.

Construct validity was tested by confirmative factor analyses. These analyses supported the 3 scales in the CSP, as used in the Scalpdx; namely, symptoms, functioning and emotions. The scores of the 3 scales of the CSP showed a significant positive correlation with both patient- and physician-reported scalp severity; this is in line with the hypothesis for the construct validity. Interestingly, the scales have higher correlations with patient's perception of the severity of the scalp psoriasis than with the physician's opinion. The correlation between both patient- and physician-reported scalp severity and the CDLQI was less strong.

Responsiveness analysis proved that the 3 scales of the CSP are sensitive to change in the expected direction in the children whose scalp psoriasis improved. In contrast to the improvement in CSP and scalp psoriasis of these children, the CDLQI and PASI deteriorated. This suggests that the CDLQI is not specific enough to reflect the QoL of children with scalp psoriasis.

In conclusion, the CSP proved to be reliable, responsive and valid for the assessment of QoL of children with scalp psoriasis. The CSP can be used as a targeted questionnaire in the evaluation of outcome assessments and the effect of therapeutic interventions on QoL in children with scalp psoriasis.

*The authors declare no conflicts of interest.*

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