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Characterising Treatment-related Patient Needs in Atopic Eczema: Insights for Personalised Goal Orientation

Running head: Patient Needs in Atopic Eczema

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Abstract

Background: Atopic eczema (AE) is a common and burdensome chronic skin disease. Clinical guidelines suggest an evidence-based, personalised, stepwise treatment approach. Only few studies have so far focused on the specific patient needs in treatment.

Objectives: To characterise therapeutic needs of patients with AE in routine care.

Methods: Nationwide cross-sectional study in 91 dermatology practices and outpatient clinics. Descriptive statistics were used for valuation. Comparisons of HRQoL and general health status were performed including subgroups (age, gender, disease duration). Group comparisons of patient needs were performed for age groups, gender and disease duration. Correlations between patients' needs (PNQ) and HRQoL, generic health status and severity were tested. In addition, a hierarchical regression analysis was performed to determine which variables contribute to explain the variance in patient needs.

Results: Analysis of 1,678 patients (60.5% female, mean age 38.35 ± 15.92 years) revealed a high disease burden with mean SCORAD of 42.26 ± 18.63 , mean DLQI of 8.49 ± 6.45 , and mean EQ-VAS of 63.62 ± 21.98 .

Among the patient needs that were most frequently rated as "quite important"/"very important" were: "to be free of itching" (96.0%), "to get better skin quickly" (7.8%), and "to be healed of all skin defects" (85.7%). In general, older people, women and patients who had been diagnosed with AE for one year or less rated the treatment needs as more important than younger patients, men and patients who had been diagnosed with AE for more than one year. Major determinants of higher needs were skin-related quality of life impairments, higher disease severity, and higher age.

Conclusions: Patients with AE show a high number and variety of therapeutic needs related to disease signs and symptoms, which are associated with individual disease burden. The patient needs vary substantially according to patient characteristics. Identification of patient-specific needs may support personalised, patient-centred care, and shared decision making.

Key words: disease burden, treatment preferences, health-related quality of life, atopic eczema, itch, Patient Benefit Index

Introduction

Atopic eczema (AE) is a chronic, inflammatory, itchy skin condition that usually develops in early childhood but may affect people of all age groups. With up to 20% in children and 1-3% in adults, the disease is characterised by an increasing prevalence within the last decades¹⁻³.

AE is associated with other atopic symptoms like allergic rhinitis, allergic conjunctivitis, and asthma⁴. Many people with AE suffer from intensely pruritic skin^{5,6}. Clinical experience and several studies have shown that people with AE experience impairments in their health-related quality of life (HRQoL), including all dimensions of HRQoL such as physical and emotional well-being⁷⁻¹⁴. HRQoL impairment not only affects the patient but also their social environment such as family members and is related to the perception of treatment¹⁵.

Given the significant impact of AE on HRQoL of patients and families, addressing psychosocial issues is of great importance in disease managing¹⁶.

A key element of clinical decisions is the inclusion of the patients' perspective. To do so, most clinicians discuss the individual disease burden and potential losses of HRQoL. Beyond that, the agreement on defined treatment goals is of great help for stringent therapeutic management. However, only few publications have focussed on the question of how to define, measure and re-evaluate treatment goals and outcomes from the patients' perspective. In recent years, such a methodology was developed in dermatology. This methodology evaluates patient needs before therapy, translates them into treatment goals and checks goal achievement after or along the treatment course. This approach, called Patient Benefit Index (PBI) was validated for a set of different dermatological diagnosis in a standard version¹⁷, is currently being validated specifically for AE. However, there is still a lack of systematic data characterising patient needs in this indication.

In the current study the following research questions were thus addressed:

1. How impaired is the HRQoL of patients with AE? Are there HRQoL differences according to sex, age groups, or disease duration?
2. Do patient needs differ between sex, age, and disease duration groups?
3. To what extent are patient needs associated with generic QoL, skin-generic QoL, and disease severity?
4. Which factors explain the variance in patient needs?

Patients and Methods

Study design and procedures

A non-interventional cross-sectional nationwide survey (AtopicHealth) on patients with AE based on standardised questionnaires was completed by the patient and the dermatologist. Approval was obtained from the ethics commission of the State Medical Association of Hamburg before the start of the study.

Centres and patients were selected with a two-step cluster sample method, with recruitment by random and by choice. Nationwide, a random sample of 604 dermatological practices and outpatient clinics was contacted. Of these, 458 dermatologists were drawn on the basis of chance among the total pool (N = 3,217) of office-based dermatologists in Germany with membership in the Professional Association of German Dermatologists; 130 centres were selected due to their active participation in the 2007 national health care study about psoriasis (PsoHealth); and 16 centres were recruited due to their activity as advisory board members within this study. A total of 174 centres agreed to participate and were sent the study documents and questionnaires (response rate 28.8%). Out of these 174 centres, 91 (52.3%) were actively recruited patients.

Patients were included in the study if they met the following inclusion criteria: (1) 18 years of age or older; (2) clinical diagnosis of AE; (3) written consent to participate in the survey.

Overall, 3,720 questionnaires from physicians and 3,644 questionnaires from patients were returned to the study centre between January and December 2010. Of these, 3,979 (54%) questionnaires were not completed and thus were excluded. Also, 38 patient-physician dyads of questionnaires were excluded because they did not meet the inclusion criteria and

6 were excluded due to crucially conflicting statements in the patient and physician questionnaire. A further 108 questionnaires could no longer be considered due to late delivery. Therefore, 1,678 data sets were entered for analysis.

Outcomes

The study protocol included a patient questionnaire assessing sociodemographic characteristics (e.g., age, gender, marital status, education, job) and clinical data (e.g., year of diagnosis, current symptoms, treatment in the past seven days, subjective symptoms related to pruritus and lack of sleep (on a scale ranging from 0 = not present to 10 = very strong/worst itch imaginable).

Skin-generic HRQoL was assessed with the Dermatology Life Quality Index (DLQI)¹⁰. This dermatology-generic questionnaire includes ten items (e.g., “Over the last week, how embarrassed or self-conscious have you been because of your skin?”), to be answered in a 4-point Likert scale ranging from 0 (“not at all”) to 3 (“very much”). A total sum score ranging from 0 to 30 was computed, with higher scores indicating greater impairment.

Generic health status was assessed with the EQ visual analogue scale (EQ-VAS)¹⁸. The EQ-VAS ranges from 0 (“the worst health you can imagine”) to 100 (“the best health you can imagine”) and was used to characterise the subjective health status, using “today” as time reference.

The evaluation of therapeutic is the first part of the Patient Benefit Index (PBI), and includes a standardised list of items. The PBI has been validated for many different skin diseases^{17,19,20}. The PNQ for AE includes 25 items to be rated by the patients with respect to importance for treatment on a 5-point Likert scale ranging from 0 (“not important at all”) to 4 (“very important”); the option “does not apply to me” is also available.

In addition, the physicians also rated the characteristics of AE based on criteria from Hanifin and Rajka²¹, disease severity based on the SCORAD²² index (SCORing Atopic Dermatitis) subjective symptoms related to pruritus and lack of sleep as part of the SCORAD (in a scale ranging from 0 = not present to 10 = very strong). Within the SCORAD the extent (A) should be classified between 0 and 100% of the body surface. Each of the six intensity items (B) were evaluated on a scale from 0 (absent) to 3 (severe) and summed up. The two subjective criteria (C) (itching and sleep loss) were rated on a scale from 0 (not affected at all) to 10 (severely affected) and summed up. The SCORAD was calculated as follows: $A/5 + 7*B/2 + C$. It can reach values between 0 and 103, with a higher SCORAD indicating higher severity of AD. It was not calculated in case of missing values. Besides, the global clinical assessment of atopic eczema (scale ranging from 0 = “clear” to 4 = “severe” AE) and treatment adherence in a scale from 0 = “almost never” to 3 = “almost always”) were assessed.

Statistical evaluation

Statistical analyses were conducted with SPSS version 23.0 (SPSS Inc., Chicago, IL). Descriptive statistics (absolute/relative frequencies for categorical variables; medians, mean scores and standard deviation [SD] for continuous variables) were used for valuation. The level of significance was set at $p < 0.05$.

Comparisons of HRQoL and general health status (DLQI and EQ-VAS scores) between the study sample and results obtained from the previous AtopicReal study²³ were performed with one-sample t-tests. Differences between men and women, between age groups (i.e., emerging adults between 18 and 30 years of age vs. adults between 31 and 64 years vs. elderly over 65 years of age), and disease duration groups (i.e., < 1 year vs. ≥ 1 year) were tested with independent-samples t-tests or one-way ANOVAs with post-hoc comparisons with Bonferroni correction.

For group comparisons of patient needs across age groups, Kruskal-Wallis tests following a chi-squared distribution were performed; differences between sex and disease duration were tested with Mann-Whitney U tests.

Correlations between patients' needs (PNQ) and HRQoL, generic health status and severity (DLQI, EQ-VAS, SCORAD) were tested with Pearson correlations coefficient (r). In addition, a hierarchical regression analysis was performed to determine which variables contribute to explain the variance in patient needs (mean across all items), entering the sociodemographic variables (age and sex) in the first block, the clinical variables (disease duration and severity) in the second block, and HRQoL and general health status in the third block of the regression equation.

Results

Study participants

A total of 1,678 patients with AE were analysed (60.5% female, mean age 38.35 ± 15.92 years, range 18-98). The participants' sociodemographic characteristics are presented in Table 1.

Clinical severity and treatment

The clinical features of AE are displayed in Table 2. Among the specific symptoms reported by patients, dry skin (93.2%) and itching during sweating (72.5%) were the most frequent.

On average, 10.4% of the patients' body surface was affected by AE foci in a body grid. The most commonly used therapies (reported by patients) in the previous five years were ointments/basic care (90.4%) and topical corticosteroids (85.5%). On average, the

respondents rated the quality of treatment of AE over the last few years with 2.6 ± 0.9 (1 = “very good”, 5 = “insufficient”). Based on the PNQ and the Patient Benefit Questionnaire (PBQ) the patient-defined therapy benefit (PBI) was calculated and averaged 2.43 ± 1.08 .

Health-related quality of life

The total skin-generic HRQoL (DLQI) was 8.49 ± 6.45 . Following the classification by Hongbo²⁴, 32.1% of patients suffered from a severe (DLQI total scores between 11 and 20) or very severe (DLQI total scores between 21 and 30) loss of QoL. The general health status (EQ-VAS) was 63.62 ± 21.98 . There were no significant gender differences in HRQoL, either as assessed by the DLQI (men: 8.40 ± 6.30 ; women: 8.55 ± 6.55 , $t_{(1.589)} = -0.47$, $p = 0.64$) or by the EQ-VAS (men: 64.00 ± 21.28 ; women: 63.37 ± 22.44 , $t_{(1.575)} = 0.55$, $p = 0.58$). However, significant differences were found between age groups ($F_{(2.1585)} = 12.42$, $p < 0.001$ for the DLQI scores; $F_{(2.1571)} = 4.33$, $p < 0.01$ for the EQ-VAS). Specifically, the elderly presented significantly lower skin-generic HRQoL than the adults (mean difference = -2.71 , $SE = 0.61$, $p < 0.001$) or the emerging adults (mean difference = -3.11 , $SE = 0.62$, $p < 0.001$) and the adults reported lower generic health status when compared to emerging adults (mean difference = -2.84 , $SE = 1.16$, $p = 0.04$). Regarding disease duration, significant differences in skin-generic HRQoL were also found between patients with AE diagnosis for one year or less and patients diagnosed more than one year ago (≤ 1 year: 6.75 ± 5.28 ; > 1 year: 8.77 ± 6.58 , $t_{(1.473)} = -3.24$, $p < 0.001$), but no significant differences for generic health status as assessed with the EQ-VAS (≤ 1 year: 65.98 ± 21.76 ; > 1 year: 63.42 ± 21.83 , $t_{(1.460)} = 1.21$, $p = 0.23$).

Patient needs

The patient needs relating to treatment goals rated as “quite important” or “very important” most frequently were “to be free of itching” (96.0%), “to get better skin quickly” (87.8%) , “to be healed of all skin defects” (85.7%), “to no longer have burning sensations on your skin” (83.0%), “to regain control of disease” (81.9%) and “to have confidence in therapy” (81.2%) (Table 3). Conversely, a high proportion of patients reported that "having more contact with other people" (38.9%), “to be able to lead a normal working life” (48.4%) and “being able to lead a normal sex life” (38.7%) were treatment goals not applicable to them. Nevertheless, patients to whom these treatment goals were applicable rated them as “important” or “very important”: "having more contact with other people" (66.9%), “to be able to lead a normal working life” (81.0%) and “being able to lead a normal sex life” (71.2%).

Subgroups of patient needs

Group comparisons identified statistically significant differences by age, gender, and disease duration groups (Figs. 1-3).

Differences in treatment goals by age group

Comparisons across age groups (emerging adults ≤ 30 vs. adults 31-64 vs. elderly ≥ 65 years) revealed significant differences for 18 out of 25 PNQ items (Fig. 1). In general, younger patients rated all treatment goals as less important than the adults did, and the adults rated most needs as less important than the elderly did. The largest differences were found for the needs of “to have fewer side effects” (2.85 in emerging adults vs. 3.20 in adults vs. 3.44 in elderly, $\chi^2 = 41.91$, $p < 0.001$), “to experience a greater enjoyment of life” (3.10 in emerging

adults vs. 3.40 in adults vs. 3.48 in elderly, $\chi^2 = 23.14$, $p < 0.001$), “to have confidence in the therapy” (3.44 in emerging adults vs. 3.61 in adults vs. 3.68 in elderly, $\chi^2 = 20.85$, $p < 0.001$), and “to feel less depressed” (2.97 in emerging adults vs. 3.23 in adults vs. 3.35 in elderly, $\chi^2 = 19.07$, $p < 0.001$). The only remarkable exception was observed for the need of “to be able to have a normal sex life”, which was rated as less important by the elderly when compared to adults ($Z = -2.11$, $p = 0.04$).

Differences in treatment goals by sex

Out of the 25 items, there was a significant difference in 21 of them, all rated more important by women than men (Fig. 2). The greatest differences were found in the needs of “get better skin quickly” ($M \pm SD = 3.50 \pm 0.75$ for men; $M \pm SD = 3.70 \pm 0.63$ for women, $Z = -6.28$, $p < 0.001$), “be more comfortable showing yourself in public” ($M \pm SD = 2.94 \pm 1.16$ for men; $M \pm SD = 3.26 \pm 1.02$ for women, $Z = -5.23$, $p < 0.001$), “be healed of all skin defects” ($M \pm SD = 3.41 \pm 0.86$ for men; $M \pm SD = 3.59 \pm 0.78$ for women, $Z = -4.96$, $p < 0.001$), “to be able to lead a normal everyday life” ($M \pm SD = 3.28 \pm 0.97$ for men; $M \pm SD = 3.51 \pm 0.85$ for women, $Z = -4.75$, $p < 0.001$), and “to have no fear that the disease will become worse” ($M \pm SD = 3.06 \pm 1.08$ for men; $M \pm SD = 3.30 \pm 1.02$ for women, $Z = -4.75$, $p < 0.001$).

Differences in treatment goals by disease duration

Out of the 25 items, there was a significant difference in six of them with regard to disease duration. All of them were rated higher by patients with a shorter disease duration (Fig. 3). The following treatment needs were found to have the most considerable significant differences: “to have no fear that the disease will become worse” ($M \pm SD = 3.49 \pm 0.86$ for duration ≤ 1 year; $M \pm SD = 3.17 \pm 1.07$ for duration > 1 year, $Z = -2.85$, $p = 0.004$), “to be

healed of all skin defects" ($M \pm SD = 3.68 \pm 0.67$ for duration ≤ 1 year; $M \pm SD = 3.49 \pm 0.82$ for duration > 1 year, $Z = -2.48$, $p = 0.013$), "to find a clear diagnosis and therapy" ($M \pm SD = 3.72 \pm 0.63$ for duration ≤ 1 year; $M \pm SD = 3.54 \pm 0.84$ for duration > 1 year, $Z = -2.31$, $p = 0.021$), and "to have confidence in the therapy" ($M \pm SD = 3.69 \pm 0.66$ for duration ≤ 1 year; $M \pm SD = 3.52 \pm 0.81$ for duration > 1 year, $Z = -2.18$, $p = 0.029$) .

Associations of patient needs with severity and health-related quality of life

Significant but low correlations between patient needs (PNQ items) and generic health status (EQ-VAS), skin-generic HRQoL (DLQI), and disease severity (SCORAD) were observed in a noticeable number of items (Table 4).

Results from the regression analyses examining the main effects of sociodemographic, clinical, and HRQoL variables on the mean score of all patient needs are displayed in Table 5. Significant main effects of age, disease severity, and skin-generic HRQoL were found, explaining a total of 10% of the variance in patient needs. Specifically, older age, higher severity, and greater HRQoL impairments were associated with patients reporting increased needs related to AE treatment.

Discussion

This study was carried out to obtain information about the needs and related therapeutic goals of patients with AE. The rationale for this study was the insight that an important component of decision making in the care of chronic skin diseases is the patients' need.

Within this background, a nationwide study of 1,678 patients, and thus with a sufficient number of cases in routine care, determined the number and type of needs of patients with

AE. As in previous studies on AE, the reduction of pruritus was the most important therapeutic goal and even ranks before the healing of all skin lesions. This argues for a regular assessment of pruritus intensity during care of AE patients besides monitoring of the skin lesions²⁵ as recommended. However, many other potential needs are also important. Only in this overall view of therapeutic benefits, which can go far beyond the clinical degree of absence of visible symptoms, the value of a therapy can be recognised.

Regarding HRQoL, the results show that patients with AE experience severe impairments. The total skin-generic HRQoL (DLQI) was 8.49 ± 6.45 . This mean score is not significantly different from the one found in a previous study (for comparison: $M \pm SD$ in AtopicReal: 8.5 ± 6.0 , $t_{(1,590)} = -0.05$, $p = 0.96$)²³. The general health status (EQ-VAS) was 63.62 ± 21.98 (AtopicReal: 61.9 ± 22.0)²³, indicating significant losses of perceived health ($t_{(1,576)} = 3.10$, $p = 0.002$).

There were no significant gender differences in HRQoL and general health status. However, significant differences were found across age groups. The elderly reported significantly lower skin-generic HRQoL than the adults or the emerging adults and the adults reported lower general health when compared to emerging adults. This might be explained by the impairments related to aging, such as reduced mobility, greater difficulties in self-care, and in performing everyday activities. Regarding disease duration, patients with AE diagnosis for one year or less reported higher impairments in skin-generic HRQoL than patients who had been diagnosed for more than one year. One explanation could be that patients who had been diagnosed for less than one year had not adjusted to the disease in terms of finding an effective coping style yet. The average PBI was 2.43 ± 1.08 , which was significantly lower than the benefit found for the patients in AtopicReal ($M \pm SD = 2.1 \pm 1.1$, $t_{(1,416)} = 11.34$, $p < 0.001$) and indicates moderate average benefits from treatment.

With regard to patient needs, results show that these patient needs are of high importance to patients with AE. Even though some needs (e.g. to be able to lead a normal working life) are less applicable to the overall group of patients e.g. due to retirement, results have shown that nevertheless they are highly important to patients who rated these goals as applicable. Group comparisons identified statistically significant differences by age, gender, and disease duration. The group of younger patients rated all treatment goals as less important than the adults did, and the adults rated most needs as less important than the elderly did. Differences were found for the needs of “have fewer side effects”, “experience a greater enjoyment of life”, “have confidence in the therapy”, and “feel less depressed”. These results are similar to other indications such as psoriasis²⁶ and can be explained by perceiving greater subjective health impairments while being older, the disease is expected to last longer and therefore overall more treatments have been unsatisfactory resulting in a loss of confidence in therapy, loss in enjoyment of life, and becoming depressed. The only expected exception consistent with other needs studies²⁷ was observed for the need of “be able to have a normal sex life”, which was rated as less important by the elderly than by adults.

With regard to gender, the greatest differences were found in the needs of “get better skin quickly”, “be more comfortable showing yourself in public”, “be healed of all skin defects”, “be able to lead a normal everyday life”, and “to have no fear that the disease will become worse”, rated more relevant by women than by men. All of these patient needs are related to the visibility of disease symptoms as well as to the need of a health locus of control²⁷.

The following treatment needs were found to have the most considerable differences, rated higher by patients with a disease duration of one year or less: “to have no fear that the disease will become worse”, “to be healed of all skin defects”, “to find a clear diagnosis and

therapy”, and “to have confidence in the therapy”. These results are in contrast to a previous study, where disease duration was found to play an important role in the burden experienced by patients with itching dermatoses, whereas patients with a longer disease duration experienced higher burden²⁸.

Thus, results indicate that individual patient characteristics such as age, gender, duration of illness, and many other factors that make a patient's need and benefit profile unique needs to be considered.

Though mostly significant, there was a remarkably low level of correlation between the patient needs items and the DLQI. This may indicate that the construct of patient needs is markedly different from disease burden measured by HRQoL and therefore need to be obtained additionally. Higher age, higher severity and greater HRQoL impairments were associated with patients reporting increased needs related to AE treatment, supporting the hypothesis that with higher impairment, people also have more needs for treatment. For clinical practice it is advisable to determine the variety of patient needs and possible therapy goals in advance in order to bring about an individualised therapeutic decision. Only based on these personalised therapy decisions, the claim for shared-decision making in therapy can be maintained.

The present methodology of needs assessment for defining therapy goals represents an important basis for any clinical decision making and is supplemented by continuous evaluation of goal achievement throughout the course of treatment.

AE, a common, severe, and chronic skin disease, is a particularly relevant indication in which it is important to determine systematically the differentiated needs profiles of patients from patients’ perspective.

In summary, patients with AE show a high number and a high variety of therapeutic goals, which are associated with individual disease burden. Needs vary significantly different across sociodemographic and clinical subgroups. Identification of patient-specific needs and goals may support personalised, patient-centred care, and participation in shared decision making.

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Figure legends

Figure 1. Patient needs (PNQ score) by age groups (N = 1,678) and χ^2 -squared distribution for Kruskal-Wallis test regarding age group differences (* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$; two-tailed).

Figure 2. Patient needs (PNQ score) by gender (N = 1,678) and Z-score for Mann-Whitney U test regarding sex differences (* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$; two-tailed).

Figure 3. Patient needs (PNQ score) by disease duration (N = 1,678) and Z-score for Mann-Whitney U test regarding sex differences (* $p \leq 0.05$, ** $p \leq 0.01$; two-tailed).

Table 1 Socio-demographic characteristics of study participants (N = 1,678).

Socio-demographic characteristics		n	% relative
Gender	Male	662	39.5
	Female	1,016	60.5
	Total	1,678	100.0
Age (in years)	Emerging adults (18-30 years)	675	40.2
	Adults (31-64 years)	857	51.1
	Elderly (≥65 years)	136	8.1
	Missing	10	0.6
	Total	1,678	100.0
Educational level	No school graduation	30	1.8
	Hauptschule (grade 9)	252	15.0
	Realschule (grade 10)	627	37.4
	Fachhochschulreife/Abitur (grade 12/13)	641	38.2
	Other school graduations	30	1.8
	Missing	98	5.8
	Total	1,678	100.0
Marital status	Single	501	29.9
	Married/long-term partnership	592	35.3
	Separated/divorced	84	5.0
	Widowed	42	2.5
	Missing	459	27.3
	Total	1,678	100.0
Employment status	Full-time worker	649	38.7
	Part-time worker	249	14.8
	Student/professional training	307	18.3
	On leave	32	1.9
	Housewife	67	4.0
	Retired	160	9.5
	Unemployed	84	5.0
	Missing	130	7.8
	Total	1,678	100.0

M, Mean; SD, Standard deviation.

Table 2 Clinical characteristics of study participants.

Patient questionnaire		n	% relative	M±SD	Range
Disease duration	≤ 1 year	122	7.3	22.07±15.09	0-84
	> 1 year	1,374	81.9		
	Missing	182	10.8	-	-
	Total	1,678	100.0	-	-
Treatment (past 7 days)	Yes	1,284	76.5	-	-
	No	320	19.1	-	-
	Missing	74	4.4	-	-
	Total	1,678	100.0	-	-
Treatment adherence	Valid	1,568	93.3	2.68±0.58	0-3
	Missing	113	6.7	-	-
	Total	1,678	100.0	-	-
Satisfaction with treatment	Very satisfied	496	29.6	-	-
	Moderately satisfied	776	46.2	-	-
	Rather not satisfied	230	13.7	-	-
	Very unsatisfied	47	2.8	-	-
	Missing	129	7.7	-	-
	Total	1,678	100.0	-	-
Pruritus	Valid	1,671	99.6	5.08±2.72	0-10
	Missing	7	0.4	-	-
	Total	1,678	100.0	-	-
Lack of sleep	Valid	1,667	99.3	2.75±2.86	0-10
	Missing	11	0.7	-	-
	Total	1,678	100.0	-	-
Physician questionnaire		n	% relative	M±SD	Range
SCORAD index	Valid	1,613	96.1	42.26±18.63	0-101.4
	Missing	65	3.9	-	-
	Total	1,678	100.0	-	-
Global clinical assessment	Clear-mild	475	28.3	2.12±0.95	0-4
	Moderate-severe	1,188	70.8		
	Missing	15	0.9	-	-
	Total	1,678	100.0	-	-
Treatment adherence	Valid	1,663	98.9	2.60±0.65	0-3
	Missing	18	1.1	-	-
	Total	1,678	100.0	-	-

M, Mean; SD, Standard deviation.

Table 3 Patient therapeutic needs in atopic eczema (N = 1,619).

No.	Treatment goal	Does apply (%)	Does not apply (%)	Missing (%)	Mean*	SD*	Important/very important (%)*	Important/very important (%)**
1	... be free of pain	74.9	23	2.1	3.5	0.8	67.4	90
2	... be free of itching	98.6	0.6	0.8	3.8	0.5	96	97.4
3	... no longer have burning sensations on your skin	88.3	9.7	2	3.7	0.7	83	94
4	... be healed of all skin defects	96.6	1.7	1.7	3.5	0.8	85.7	88.7
5	... be able to sleep better	76.2	22.3	1.5	3.4	1	63.9	83.9
6	... feel less depressed	71	27.5	1.5	3.1	1.1	54.1	76.2
7	... experience a greater enjoyment of life	74.3	24	1.7	3.3	1	61.4	82.6
8	... have no fear that the disease will become worse	82.9	15.7	1.4	3.2	1.1	65	78.4
9	... be able to lead a normal everyday life	77.4	21.3	1.3	3.4	1	67.2	86.8
10	... be more productive in everyday life	71.7	26.2	2.1	3.2	1	57.4	80
11	... be less of a burden to relatives and friends	66.1	32.4	1.5	2.9	1.2	45.1	68.3
12	... be able to engage in normal leisure activities	71.3	27.1	1.6	3.2	1	57.1	80.1
13	... be able to lead a normal working life	59.7	38.2	2.1	3.3	1.1	48.4	81
14	... be able to have more contact with other people	58.2	39.9	1.9	2.8	1.3	38.9	66.9
15	... be comfortable showing yourself more in public	76.1	21.5	2.4	3.1	1.1	58.1	76.4
16	... be less burdened in your partnership	62.8	35.5	1.7	3.1	1.2	46.2	73.6
17	... be able to have a normal sex life	54.3	43.1	2.6	2.9	1.3	38.7	71.2
18	... be less dependent on doctor and clinic visits	84.9	13.5	1.6	3.1	1.1	63.6	74.9
19	... need less time for daily treatment	88.4	10.3	1.3	3	1.1	63.2	71.5
20	... have fewer out-of-pocket treatment expenses	85.5	13.2	1.3	3.1	1.1	64.3	75.2
21	... have fewer side effects	77.1	20.9	2	3.1	1.2	55.9	72.5
22	... find a clear diagnosis and therapy	89	9.5	1.5	3.6	0.8	79.7	89.6
23	... have confidence in the therapy	90	8.3	1.7	3.5	0.8	81.2	90.2
24	... get better skin quickly	94.8	4.1	1.1	3.6	0.7	87.8	92.6
25	... regain control of the disease	89.8	9.1	1.1	3.6	0.8	81.9	91.2

*numbers relate to all people; **numbers relate to people to whom the goal applies; patient needs scale: 0=not relevant to 4=very important.

Table 4 Correlations between patient needs and different measures of severity (SCORAD), disease-specific and generic quality of life (N = 1,619).

No.	PNQ items	EQ-VAS	DLQI	SCORAD
1	... no longer have pain	-0.05	0.02	0.05
2	... be free of itching	-0.03	0.09**	0.11**
3	... no longer have burning sensations on your skin	-0.06*	0.10**	0.09**
4	... be healed of all skin defects	-0.03	0.04	-0.02
5	... be able to sleep better	-0.08**	0.09**	0.12**
6	... feel less depressed	-0.18**	0.18**	0.09**
7	... experience a greater enjoyment of life	-0.16**	0.16**	0.06
8	... have no fear that the disease will become worse	-0.08**	0.08**	0.03
9	... be able to lead a normal everyday life	-0.10**	0.17**	0.07*
10	... be more productive in everyday life	-0.13**	0.14**	0.08*
11	... be less of a burden to relatives and friends	-0.13**	0.16**	0.12**
12	... be able to engage in normal leisure activities	-0.10**	0.17**	0.08**
13	... be able to lead a normal working life	-0.10**	0.11**	0.06
14	... be able to have more contact with other people	-0.06	0.10**	0.06
15	... be comfortable showing yourself more in public	-0.12**	0.21**	0.08*
16	... be less burdened in my partnership	-0.07*	0.17**	0.07*
17	... be able to have a normal sex life	-0.01	0.15**	0.05
18	... be less dependent on doctor and clinic visits	-0.11**	0.12**	0.11**
19	... need less time for daily treatment	-0.14**	0.16**	0.13**
20	... have fewer out-of-pocket treatment expenses	-0.13**	0.10**	0.09**
21	... have fewer side effects	-0.10**	0.04	0.04
22	... find a clear diagnosis and therapy	-0.08**	0.10**	0.08**
23	... have confidence in the therapy	-0.07*	0.01	0.05
24	... have a quick improvement of the skin	-0.11**	0.07**	0.05*
25	... regain control of the disease	-0.13**	0.14**	0.12**

* $p \leq 0.05$; ** $p \leq 0.01$, two-tailed.

Table 5 Variables associated with patient needs (n = 1,309).

	Step 1: Sociodemographic variables			Step 2: Clinical variables			Step 3: General health/HRQoL		
	$\Delta R^2 = 0.03$			$\Delta R^2 = 0.02$			$\Delta R^2 = 0.05$		
	$\Delta F_{(2,350)} = 4.50^*$			$\Delta F_{(2,348)} = 4.46^*$			$\Delta F_{(2,346)} = 8.87^{***}$		
	β	t	95%CI	β	t	95%CI	β	t	95%CI
Gender	0.03	0.61	-0.10/0.18	0.07	1.28	-0.05/0.24	0.05	0.97	-0.07/0.21
Age	0.16	2.95**	0.00/0.01	0.16	2.97**	0.00/0.01	0.19	3.56***	0.00/0.02
Disease duration				0.04	0.74	-0.19/0.42	0.02	0.40	-0.24/0.36
SCORAD				0.15	2.81**	0.00/0.01	0.04	0.75	-0.00/0.01
DLQI							0.23	3.61***	0.01/0.03
EQ-VAS							-0.03	-0.49	-0.00/0.00
Model summary	$R^2 = 0.03$			$R^2 = 0.05$			$R^2 = 0.10$		
	$F_{(2,350)} = 4.50^*$			$F_{(2,348)} = 4.52^{**}$			$F_{(2,346)} = 6.11^{***}$		

^a Gender: 0  male; 1  female; * p

≤ 0.05 , ** $p \leq 0.01$, *** $p \leq 0.001$, two-tailed.





