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Atopic eczema score of emotional consequences— a questionnaire to assess emotional consequences of atopic eczema

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Abstract
Purpose Atopic eczema (AE, atopic dermatitis), one of the most common chronic skin diseases worldwide, can dramatically influence the lives of affected patients as well as the lives of their families. Despite the availability of several questionnaires for assessing the impairment of quality of life, so far the emotional consequences of AE have received limited attention. The purpose therefore was to develop an instrument to assess the emotional consequences of AE in affected adults.
Methods The Atopic Eczema Score of Emotional Consequences (AESEC) was developed based on a review of available instruments and by consulting individuals with AE about the emotional consequences of AE through social media. Validation was performed in a test-sample, followed by a large cross-sectional study in patients with AE across nine European countries. AESEC results were compared with the Patient Oriented Eczema Measure (POEM), the Dermatology Life Quality Index (DLQI) and the Hospital Anxiety and Depression Scale (HADS).
Results A 28-item questionnaire on emotional consequences of having AE was developed. Applied to 1189 participants, AESEC showed high reliability and correlated well with DLQI, HADS and POEM. More than half (57%) of the respondents were emotionally burdened. Large to very large emotional consequences were reported by 43.8% of those with currently moderate AE, 62.2% with severe AE and 66.7% with very severe AE-symptoms.
Conclusion AESEC is a questionnaire for assessing the emotional consequences of living with AE. It may prove useful in evaluating the burden of disease, beyond skin symptoms and time-specific quality of life.

Keywords Atopic dermatitis · Emotional burden · Questionnaire development · Burden of disease · Quality of life

Abbreviations

AE	Atopic eczema (atopic dermatitis)
AESEC	Atopic Eczema Score of Emotional Consequences
CATI	Computer Assisted Telephone Interview
DLQI	Dermatology Life Quality Index
HADS	Hospital Anxiety and Depression Scale
HOME	Harmonising Outcomes Measures for Eczema initiative
POEM	Patient Oriented Eczema Measure
QoLIAD	Quality of Life Index for Atopic Dermatitis
ROC	Receiver operating characteristic
SD	Standard deviation
SF	Short form

Introduction

Affecting about 1–5% of adults and 10–20% of children in Europe, Atopic eczema (AE, atopic dermatitis) is one of the most common chronic skin diseases worldwide [1–3]. With its chronic and relapsing nature over years and decades, sometimes even life-long, the disease can dramatically influence the lives of affected patients as well as the lives of their families

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[4–6]. Working life is negatively influenced, reflecting in increased sick leave, job choices, job changes and job losses, or even disability pensions for patients severely affected [7]. Moreover, AE can have a significant impact on patients' quality of life and their mental health [8, 9]. In this context several studies have reported that patients can experience a substantial reduction in quality of life and can suffer from depression and other mental health disorders as measured with different screening and scoring tools [10]. In recent years, Finlay's Dermatology Life Quality Index (DLQI) has become one of the most commonly used tools to assess quality of life in AE affected patients [11], much more than the Skindex-29 [12]. An instrument specifically designed for AE, but rarely used, is the Quality of Life Index for Atopic Dermatitis (QoLIAD) [13]. Other more generic instruments that have been used include the Short Form (SF)-36 Health Survey [14] and the SF-12 Health Survey [15].

What all of these instruments fail to capture are the emotional consequences for people living with AE and in fact, these consequences have received limited attention so far. However, there is growing evidence that these aspects of life impairment might be substantial in AE. Several recent studies have found that AE is associated with anxiety, depressive mood and depression, stress, and even suicidal ideation [16–21]. A study conducted in Germany with 181 patients with AE found a prevalence of 21.3% for suicidal ideation of affected patients with 3.9% scoring above the cut-off indicating acute suicidality [22].

Addressing the emotional aspects in affected patients requires increased emphasis from dermatologists and other healthcare specialists treating AE. However, tools to measure and assess the impact of AE on the personal emotions are still lacking. Although tools like DQLI and Skindex-29 capture emotions, these are not AE-specific and contain only a small number of items on emotional impact. QoLIAD contains 25AE-specific items, yet not all items are on emotional consequences. The QoLIAD items are also all negatively worded, which may create negative bias, and they can only be answered with 'yes' or 'no', leaving no room for nuance. Therefore a new questionnaire was developed in order to fill this gap, carried out by the European umbrella patient organisation for AE.

Materials and methods

Development of the questionnaire items

The aim of the questionnaire was to capture and measure the emotional consequences of having AE with a patient-centric view, and it therefore should reflect the situation of people living with AE. Firstly, an extensive list of items was compiled which was based on previous experience with Quality of Life studies. Secondly, through a social media group specifically for people with AE, the over 250 group members were asked for input on a specific question: '*What personal aspects of living with atopic eczema do you think are important to know for those who do not have eczema?*' Both were combined, de-duplicated and worded as brief statements. These statements should be (re)worded in items such as: 'I …' or 'My …', should not be time specific—for example '*Over the last week…*'—and should alternate between negative and positive. As for the latter: when all statements are worded as negatives it potentially presupposes that these negatives could be applicable. And when the questionnaire is self-completed there is a possibility that participants tend to answer in the same answer-column creating negative bias. An example of an instrument that uses such alternating strategy is the much used and valued Hospital Anxiety and Depression Scale (HADS) [23]. As to force an answer and rule out the option of choosing 'neutral' or 'don't know', the following 4-point Likert scale was chosen: applies fully, somewhat applies, rather not, or does not apply at all. For negative statements, scoring would be from 3 (applies fully) to 0 (does not apply at all), whilst the positive statements score in reverse; as is the case with HADS. Translations from the devised questionnaire in English (Great Britain) into target languages were done by certified translators experienced in health care questionnaires and were checked by patients with AE from these countries on comprehension and correct use of terminology. A concept of the questionnaire was tested online in the five largest EU countries (target $n=100$). Based on the test results, the reliability, consistency and inter-item correlations were calculated and an exploratory factor analysis was carried out. Subsequently, redundant items were deleted, resulting in the final questionnaire to be used in a larger validation study. An overview can be found in Fig. 1.

Validation and real-life study

The development and use of the emotional consequences' questionnaire was part of a recent and larger project to assess the real-life burden of disease of people living with AE in Europe [24], principally because no other tools for this specific purpose were available. This questionnaire on emotional consequences was therefore embedded in a larger questionnaire, which included other validated instruments to assess the burden of disease, which made it possible to compare the outcomes with those other instruments. For assessing current AE severity, the Patient Oriented Eczema Measure (POEM) [25] was chosen, based on the recommendation by the Harmonising Outcomes Measures for Eczema initiative (HOME) [26]. POEM is a 7-item questionnaire measuring eczema symptoms over the past week, the scores can be categorized into (almost) clear, mild, moderate, severe and very severe, and it correlates well with physicians' assessed sever-

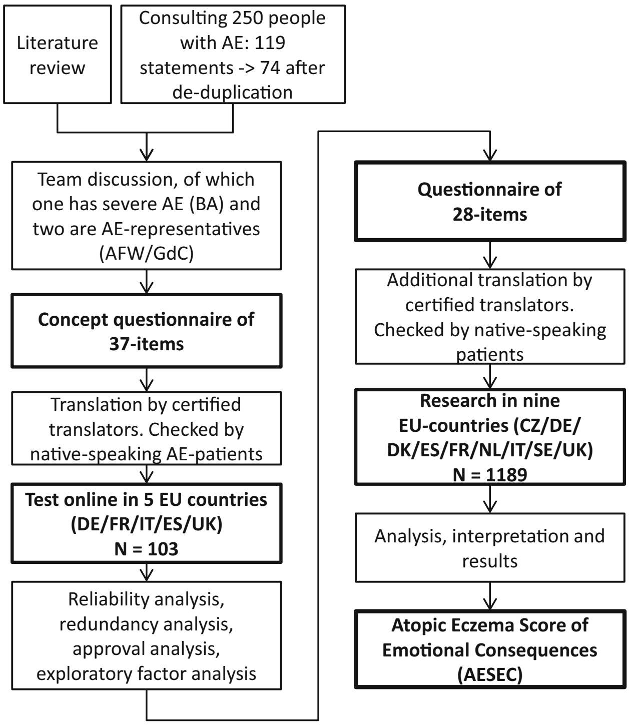

Fig. 1 AESEC development process. *AE* Atopic Eczema, *CZ* Czech Republic, *DE* Germany, *DK* Denmark, *ES* Spain, *EU* European Union, *FR* France, *IT* Italy, *NL* Netherlands, *SE* Sweden, *UK* United Kingdom

ity [27]. Measurement of the effect of AE on quality of life was undertaken using the DLQI, which categorizes the impact of dermatological diseases into no effect at all on patient's life, small effect, moderate effect, very large effect and extremely large effect [11]. To assess depressive symptoms, the 7-items relevant to depression from the Hospital Anxiety and Depression Scale (HADS-D7) were used, in which the score can be rated as: "normal", "borderline" or "abnormal" (indicating clinical 'caseness') [23].

In each country permission was requested from the local Ethics Committees and given before starting the study. Participants were recruited through physicians to ensure adherence to the inclusion criteria: 18 years or older, AE diagnosis made by a physician, current use of systemic immunomodulatory therapy or phototherapy, or candidate for systemic immunomodulatory therapy or phototherapy. Therefore these participants had moderate-to-severe AE that could not be adequately controlled by topical therapy alone, e.g. emollients and moisturisers, (very) potent topical corticosteroids and/or topical calcineurin inhibitors. The actual severity of the AE of the participant could vary, depending on the effectiveness of the therapy at the time of participation. The study was carried out in nine European countries (target *n*; total 1200): Czech Republic (50), Denmark (50), France (180), Germany (180), Italy (180), Netherlands (150), Spain (180), Sweden (50) and United Kingdom (180). The method of Computer Assisted Telephone Interview (CATI) was chosen to ensure a national coverage with the greatest possible evaluation quality. Fieldwork started October 2017 and was completed beginning of March 2018. During the telephone interview participants were asked—besides the questions on demographic details and the aforementioned instruments—for their response to the questions on emotional consequences. These were phrased by the interviewers as *"I will now read out a number of aspects that you may feel apply or do not apply to your life with Atopic Eczema. Please tell me for each individual aspect, the degree to which it applies to your situation".*

Statistical and psychometric analyses

Development of the questionnaire, its testing and subsequent analyses involved rigorous and proven statistical analyses to ensure reliability and consistency. Analyses on the reliability and consistency of the concept questionnaire were done using Cronbach's alpha (α) and Spearman's rho (ρ). Furthermore an exploratory factor analysis (orthogonal/varimax) was carried out, as was an approval analysis and a sensitivity analysis with regard to AE severity. The reliability of the final questionnaire based on the real-life results from the EU study was reported on the total set with Cronbach's α and Spearman's ρ for inter-item correlations. Reliability was further tested with a split-half analysis. A principal component analysis (three-factor analysis, orthogonal/varimax) was carried out, including factor correlations. Correlations with HADS-D7, DLQI and POEM were calculated and reported with Spearman's ρ. All statistical analyses were performed using SPSS software version 14.0 (IBM Corp., New York, NY, USA).

Results

Development of the questionnaire

Participation of adults living with AE through social media yielded 119 very personal and verbatim answers. These were de-duplicated and reworded into brief statements starting, if possible, with 'I …'or 'My …', leaving 74 items. After careful and detailed assessment of these statements with regard to overlap, ambiguity, or cultural or language specificity, and combined with the findings from the literature review, 37 items were selected by the author team. If necessary and when linguistically possible, some statements were reworded from negative into positive, resulting in a fair balance between the two. During the whole process, a native English speaker experienced in developing questionnaires was involved.

Between 18 and 22 August 2017, 103 people with AE (53.4% female/46.6% male, mean age 42 years [SD 14.3], age range 20–87) in France, Germany, Italy, Spain and the United Kingdom (20% in each country) answered the 37-item concept questionnaire online to

Table 1 Participants' characteristics

	n (%)
Total sample	1189 (100)
Gender	
Men	519 (44)
Women	670 (56)
Age	
Mean [SD]	42.1 [±11.2]
Range	18–87
18–29 years	153 (13)
30–39 years	357 (30)
40–49-years	421 (35)
≥50 years	258 (22)
Skin type	
Light-skinned	470 (40)
Intermediate	498 (42)
Dark-skinned (Mediterranean predominantly)	221 (19)
Education	
Elementary/junior high school	123 (10)
High school graduation	427 (36)
Graduated 3-year college/4-year college/university	478 (40)
Postgraduate	113 (10)
No qualification/no answer	41 (3)
AE severity (POEM)	
Clear/almost clear	195 (16)
Mild	453 (38)
Moderate	359 (30)
Severe	140 (12)
Very severe	42 (4)
Quality of life (DLQI)	
No effect	143 (12)
Small effect	388 (33)
Moderate effect	381 (32)
Very large effect	241 (20)
Extremely large effect	36 (3)
Depression (HADS-D7)	
Normal	1064 (89)
Borderline	85 (7)
Abnormal	40 (3)

AE Atopic Eczema, *POEM* Patient Oriented Eczema Measure, *DLQI* Dermatology Life Quality Index, *HADS-D7* 7 items on depression of the Hospital Anxiety and Depression Scale

enable its testing. Self-assessed disease severity was reported as 10.7% (almost) clear, 29.1% mild, 49.5% moderate and 10.7% severe. The internal consistency and reliability of the questionnaire was excellent ($\alpha=0.938$; based on moderate to severe AE: $n=62$), even when divided into parts. The sets of negative and positive items were each appraised on the approval rate and the differences between those with mild versus moderate/severe AE. Exploratory factor analysis (orthogonal/varimax) found four possible factors (cheerful/carefree, suffering/worried, overstrained, ashamed/insecure) and reliability and sensitivity analyses were carried out within each group. Furthermore, redundant items with high correlations (calculated with Spearman's ρ) were identified.

After careful consideration of all possible choices without forfeiting reliability, internal consistency or diversity, and adhering to the prespecified patient-centric requirements, 28 of the 37 items were selected by the author team by means of consensus, resulting in an item-set with excellent internal consistency and reliability ($\alpha=0.929$), and low inter-item correlation ($\rho=0.224$).

Participants EU study

A total of 1189 adults with AE (mean age 42.1 [SD 11.1], range 18–87 years; 56.3% women and 43.7% men) were interviewed (Table 1: participants' characteristics). Participants originated from Czech Republic (52), Denmark (50), France (180), Germany (180), Italy (180), Netherlands (150), Spain (180), Sweden (37) and United Kingdom (180). The majority were recruited through physicians (84%) and in certain instances, in view of restrictive country regulations or infeasibility, other means of recruitment were necessary, e.g. via support groups or recommendation. This did not compromise adherence to inclusion criteria, as the screening questions ensured eligibility. To test this adherence, the sample from the Netherlands was analysed where 48.7% were recruited through physicians and 51.3% through support groups, and data showed hardly any noticeable structural differences.

AESEC psychometrics

The reliability of the total 28-item AESEC questionnaire was high ($\alpha=0.900$) with low inter-item correlation ($\rho=0.208$). To further examine the reliability, a split-analysis was performed: reliability was high for both halves ($\alpha=0.853$ and 0.842, respectively). The equal length Spearman–Brown coefficient was 0.915, which is well over the acceptable 0.80. A factor analysis (principal component, orthogonal/varimax) was carried out (Table 2). The Kaiser–Meyer–Olkin measure of sampling adequacy was 0.952 and Bartlett's test of sphericity was significant ($\chi^2=11{,}713.89$, $df=378$, $p<0.0005$), indicating an adequate sample for factor analysis. The analysis yielded three factors with adequate loading of the 28-items over these factors, and there was no correlation between the three factors. The factors could be described as desperate/burdened, insecure/worried and balanced/satisfied. The reliability of the factors was high ($\alpha=0.802$–0.882) with a weak/moderate inter-item correlation ($\rho=0.294$–0.428). The correlations with POEM, DLQI and HADS-D7 were significant and were moderate with HADS-D7 ($\rho=0.540$), moderate with DLQI ($\rho=0.546$) and moderate with POEM

Table 2 Factor analysis 28-item AESEC questionnaire

Rotated Component Matrix[a]

	Component		
	1	2	3
Itching drives me crazy	**0.742**	0.046	0.187
I feel sad about having eczema	**0.716**	0.216	0.137
My eczema makes me angry	**0.690**	0.247	0.170
I envy people with normal skin	**0.690**	0.027	0.028
I try to hide my eczema	**0.670**	0.265	–0.002
I feel embarrassed about my skin appearance	**0.624**	0.409	0.091
I struggle with my appearance	**0.545**	0.480	0.129
I feel overwhelmed by my eczema	**0.537**	0.374	0.206
I feel guilty about scratching	**0.477**	0.277	0.124
I feel detached from others	0.137	**0.688**	0.199
I am afraid of being rejected	0.316	**0.620**	0.123
I am afraid of being a burden to my relatives	0.117	**0.617**	0.237
I have difficulties concentrating	0.257	**0.534**	0.171
I worry about my life because of my eczema	0.291	**0.529**	0.260
I try to avoid physical contact or touching other people	0.313	**0.522**	0.069
I feel insecure	0.391	**0.519**	0.253
I feel trapped because of my eczema	0.458	**0.492**	0.254
I am nervous	0.347	**0.478**	0.127
I cope well with my eczema	0.093	0.187	**0.701**
I feel I can handle my eczema	0.107	0.084	**0.668**
I am in control of my eczema	0.237	0.027	**0.657**
I am optimistic about my life with eczema	0.084	0.223	**0.592**
I am a well-rounded person	0.060	0.258	**0.564**
I am self-confident	0.044	0.372	**0.497**
I feel I can do what other people can do	0.027	0.320	**0.494**
I am a relaxed person	0.296	0.239	**0.484**
I have no problem with intimacy	0.142	–0.059	**0.452**
I feel I am good enough as a person	–0.171	0.375	**0.440**

Extraction Method: Principal Component Analysis

Rotation Method: Varimax with Kaiser Normalization

Component Score Covariance Matrix

Component	**1**	**2**	**3**
1	1.000	0.000	0.000
2	0.000	1.000	0.000
3	0.000	0.000	1.000

Extraction Method: Principal Component Analysis

Rotation Method: Varimax with Kaiser Normalization

Factors	**Description**	**Items**	**Cronbach's Alpha**	**Mean inter-item correlation**
Factor 1	Desperate/burdened	10	0.882	0.428
Factor 2	Insecure/worried	8	0.822	0.368
Factor 3	Balanced/satisfied	10	0.802	0.294

[a] Rotation converged in 6 iterations

AESEC Atopic Eczema Score of Emotional Consequences

Table 3 Correlations of AESEC with POEM, DLQI and HADS-D7

			Spearman's rho	*P*	Lower 95% CI	Upper 95% CI
AESEC	–	POEM	0.466	<0.001	0.420	0.509
AESEC	–	HADS-D7	0.540	<0.001	0.498	0.579
AESEC	–	DQLI	0.546	<0.001	0.505	0.585
POEM	–	HADS-D7	0.326	<0.001	0.275	0.376
POEM	–	DQLI	0.692	<0.001	0.662	0.721
HADS-D7	–	DQLI	0.461	<0.001	0.415	0.505

POEM Patient Oriented Eczema Measure, *DLQI* Dermatology Life Quality Index, *HADS-D7* 7-items on depression of the Hospital Anxiety and Depression Scale, *CI* confidence interval, *AESEC* Atopic Eczema Score of Emotional Consequences

(ρ = 0.466), providing an indication of construct validity (Table 3).

AESEC score banding

The mean AESEC score of the 1189 participants was 32.2 (SD 14.1; median 31) out of 0–84 (higher means more consequences). In order to give meaning to these AESEC scores, we wanted to categorize these scores into 'no/small effect', 'moderate effect', 'large effect' and 'very large effect'. The anchors we could use to categorize the scores were the POEM and DLQI scores, although the correlations were only moderate. In order to find suitable cut-off values, we used the receiver operating characteristic (ROC) curves of DLQI and POEM scores versus the total AESEC score, with some assumptions. One assumption was that participants who reported 'no effect' on quality of life measured by DLQI should not fall into the AESEC categories 'large effect' and 'very large effect', making the optimum cut-off value to be about 40. Applying the same for the POEM score 'Clear to almost clear', also demonstrated an optimum around 40. Likewise, we assumed that participants with a 'small effect' on quality of life should not fall into the category 'very large effect' on emotional consequences, demonstrating cut-off values between 50 and 53. As for the cut-off values between the categories 'no/small effect' and 'moderate effect', the optimum according to ROC analyses seemed to be between 27 and 30, for both DLQI and POEM. This was in line with the visual inspection of the data (Fig. 2).

The ROC exercise resulted in two choices: (1) 0–27 or 0–30 for 'no/small effect' and therefore 28–40 or 30–40 for 'moderate effect'; (2) 40–50 or 40–52 for 'large effect' and therefore 50–84 or 53–84 for a 'very large effect'. We analysed per AESEC category how these choices would affect the proportion of participants with regard to their severity scores of DLQI, POEM and HADS-D7. The comparison was in favour of the cut-off values 0–27 for 'no/small effect', 28–40 for 'moderate effect', 40–52 for 'large effect' and 53–84 for a 'very large effect', as this did more justice to the severity scores of DLQI, POEM and HADS (Table 4).

AESEC total scores

Of the 1189 participants, 512 (43.1%) individuals scored 'no/small consequences', 320 (26.9%) 'moderate consequences', 252 (21.2%) 'large consequences' and 105 (8.8%) 'very large consequences' (Table 5). Regardless of disease severity 56.9% of the participants reported moderate to very large emotional consequences due to living with AE. Yet those participants who experienced moderate to very severe AE symptoms, reported major effects on their lives: large to very large consequences were reported in 43.8% with moderate symptoms, 62.2% with severe symptoms and 66.7% in those with very severe AE symptoms (Table 6).

AESEC item scores

The top 5 negative items mentioned were the following: 72% of the participants reported envy of people with normal skin, 57% that itching drove them crazy, 51% tried to hide their eczema, 50% was sad due to their eczema and 43% reported that eczema made them angry (Fig. 3; Table 7). As for the top 3 positively phrased items, 39% reported to have problems with intimacy, 27% that they cannot do what other people can do, and 25% do not feel in control of their eczema (Fig. 4; Table 7).

Discussion

The AESEC questionnaire is the first available tool to specifically assess and measure the emotional consequences of people living with AE. AESEC addresses an unmet need and has shown that a scoring system on this issue was overdue: More than half (57%) of the participants are emotionally burdened, which is a new finding in the literature.

Within the last few years there have been substantial new discoveries in AE research which have made the development of new treatment strategies possible [19, 20, 28–33]. With the introduction of new treatment options and especially the approval of the first biologic for AE in the USA and EU, financial discussions have emerged [34, 35]. All the more important are full evaluations and characterizations of AE beyond the skin symptoms. AE can affect several aspects of life, which has to be acknowledged in dermatologi-

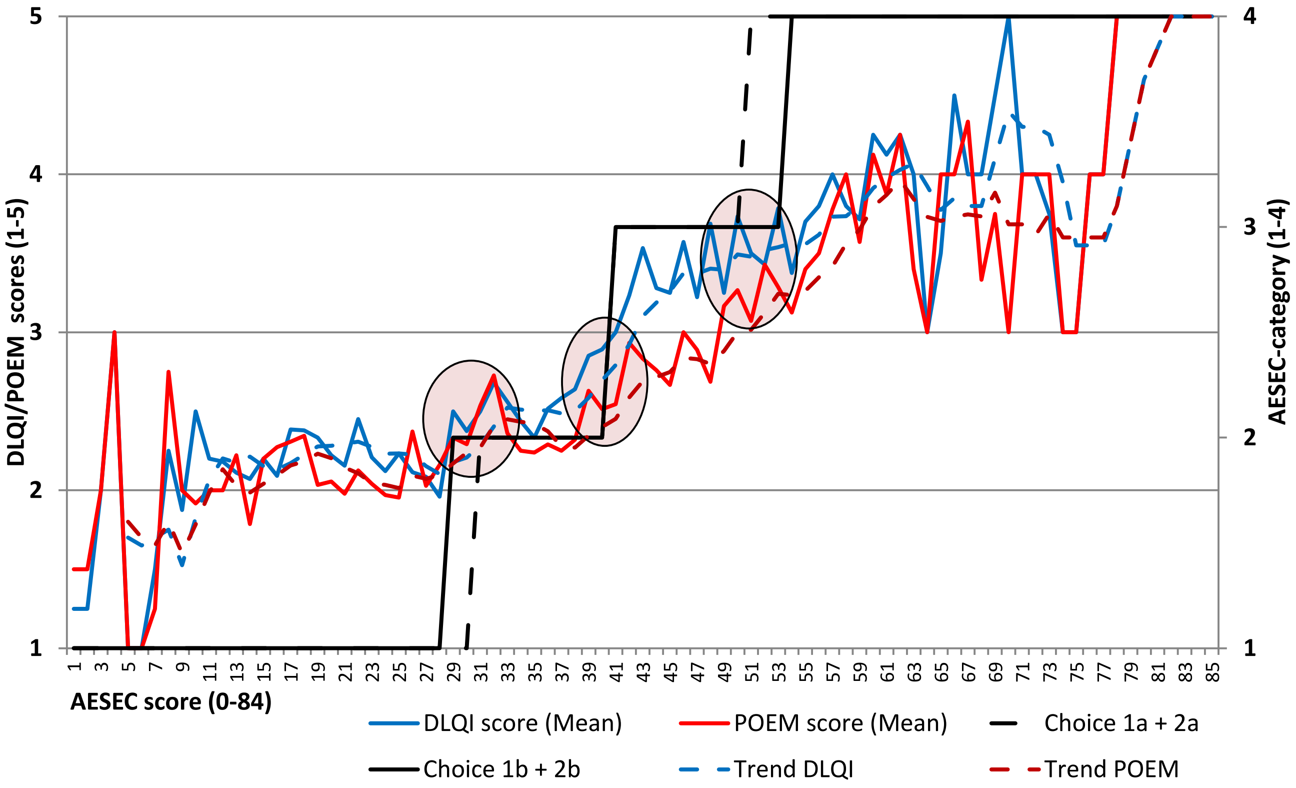

Fig. 2 AESEC score versus mean DLQI/POEM scores—two scenarios for AESEC banding. Not all scores of AESEC (0–84) were reported: score 1 was missing and between 71 and 84 eight were missing. To not distort the trend line, mean scores of POEM and DLQI for these AESEC scores were imputed with the method of *last value carried forward*

cal assessment and in choosing the best treatment for every individual with AE based on their specific needs.

Most of the previously available scoring systems for quality of life in general are based on everyday life activities and are time-specific. The DLQI for example is an excellent tool to get a first impression of quality of life in affected patients. However, the 10 questions covering symptoms, home care and shopping, social leisure, personal relationships, sexuality, treatment and embarrassment do not fully cover the impact of AE on individuals' lives affected by AE. Especially since the majority have AE (almost) all their lives, and also self-management has an impact. In addition, missing days at work, and anxiety in partnerships and families due to AE, have a negative influence on personal well-being and emotional health [14, 16, 17]. This became evident in our study because DLQI only moderately correlated with AESEC. The goal of all healthcare professionals should therefore be not only to treat the affected skin of patients with AE but rather go beyond the skin with a target-oriented approach based on individual suffering. This is in line with the recent report 'Rosacea: beyond the visible' that concluded that absence of symptoms of rosacea—a chronic skin condition affecting the face—does not necessarily mean that quality of life is not impaired [38]. For assessing the emotional consequences of living with AE, the AESEC can be used, giving insight into the emotional burden, both as an overall score or, if wanted, in more detail. The results of our study clearly reveal that this burden is substantial.

AESEC is per design structured in both negative and positive statements, as previously explained, unlike DLQI, Skindex-29 and QoLIAD. On some aspects this was a bold choice, as for example it did not enquire if people with AE had problems with intimacy, yet they were purposely asked to answer to the statement '*I have no problem with intimacy*', which is innately a different question. Therefore, items that are positively phrased really reveal negative emotions when they were answered with 'rather not' or 'does not apply at all'. These negative scores on the positively phrased items underline previous publications which seek to address psychosocial aspects of AE by for example patient education programmes [16, 36, 37] The most commonly reported items revealing negative emotions were "*I try to hide my eczema*", "*I envy people with normal skin*" and "*I feel sad about having eczema*", which clearly show the burden of disease that should be considered by all healthcare professionals treating AE.

One of the main strengths of the study is the inclusion of over one thousand patients with AE across nine European countries. Furthermore, the methodology of development and validation by including patients via social media proved, in our opinion, to be very powerful to really be able to grasp the emotional

Table 4 AESEC scoring and banding choices

	DLQI	POEM	HADS		DLQI	POEM	HADS
Choice 1a				**Choice 1b—preferred**			
No/small effect 1 = 0–29	**1 = 15.8%**	1 = 24.0%	1 = 99.3	No/small effect 1 = 0–27	**1 = 17.5%**	1 = 24.6%	1 = 99.2%
	2 = 47.3%	2 = 28.8%	2 = 0.7%		2 = 47.6%	2 = 29.4%	2 = 0.8%
	3 = 28.8%	3 = 30.1%	3 = 0%		3 = 29.4%	3 = 29.4%	3 = 0%
	4 = 8.2%	4 = 11.6%	–		4 = 5.6%	4 = 11.9%	–
	5 = 0%	**5 = 5.5%**	–		5 = 0%	**5 = 4.8%**	–
Moderate effect 2 = 30–39	1 = 5.3%	1 = 18.9%	1 = 97.9%	Moderate effect 2 = 28–39	1 = 5.2%	1 = 19.1%	1 = 98.3%
	2 = 41.1%	2 = 20.0%	2 = 1.1%		2 = 41.7%	2 = 20.9%	2 = 0.9%
	3 = 29.5%	3 = 38.9%	3 = 1.1%		3 = 28.7%	3 = 38.3%	3 = 0.9%
	4 = 23.2%	4 = 18.9%	–		4 = 23.5%	4 = 17.4%	–
	5 = 1.1%	5 = 3.2%	–		5 = 0.1%	5 = 4.3%	–
Choice 2a				**Choice 2b—preferred**			
Large effect 3 = 40–49	1 = 0%	1 = 8.6%	1 = 87.7%	Large effect 3 = 40–52	1 = 0%	1 = 8.5%	1 = 87.2%
	2 = 17.3%	2 = 21.0%	2 = 9.9%		2 = 17.0%	2 = 20.2%	2 = 10.6%
	3 = 30.9%	3 = 37.0%	3 = 2.5%		3 = 31.9%	3 = 36.2%	3 = 2.1%
	4 = 42.0%	4 = 27.2%	–		4 = 41.5%	4 = 28.7%	–
	5 = 9.9%	5 = 6.2%	–		5 = 9.6%	5 = 6.4%	–
Very large effect 4 = 50++	1 = 0%	1 = 1.7%	1 = 70.7%	Very large effect 4 = 53++	1 = 0%	1 = 0%	1 = 66.7%
	2 = 6.9%	2 = 5.2%	2 = 13.8%		2 = 4.4%	2 = 2.2%	2 = 13.3%
	3 = 22.4%	3 = 32.8%	**3 = 15.5%**		3 = 17.8%	3 = 33.3%	**3 = 20.0%**
	4 = 46.6%	4 = 34.5%	–		4 = 48.9%	4 = 33.3%	–
	5 = 24.1%	**5 = 25.9%**	–		**5 = 28.9%**	**5 = 31.1%**	–

HADS Scoring: 1 = Normal, 2 = Borderline, 3 = Abnormal
POEM Scoring: 1 = Clear/almost clear, 2 = Mild eczema, 3 = Moderate eczema, 4 = Severe eczema, 5 = Very severe eczema
DLQI Scoring: 1 = No effect on patients' life, 2 = Small effect on patients' life, 3 = Moderate effect on patients' life, 4 = Very large effect on patients' life, 5 = Extremely large effect on patients' life
POEM Patient Oriented Eczema Measure, *DLQI* Dermatology Life Quality Index, *HADS-D7* 7-items on depression of the Hospital Anxiety and Depression Scale, *AESEC* Atopic Eczema Score of Emotional Consequences

Table 5 AESEC scores

	Total	Score 1 (0–27) 'no/small'	Score 2 (28–39) 'moderate'	Score 3 (40–52) 'large'	Score 4 (53–84) 'very large'
Number	1189	512	320	252	105
Percent	100	43.1	26.9	21.2	8.8
Mean	32.22	19.38	33.76	44.63	60.38
Median	31	21	34	44	59
Standard deviation	14.07	5.650	3.511	3.671	6.319

AESEC Atopic Eczema Score of Emotional Consequences

Table 6 AESEC compared to current AE severity measured by POEM

N = 1189		AESEC Score (0–84)			
		Score 1 (0–27) 'no/small' (%)	Score 2 (28–39) 'moderate' (%)	Score 3 (40–52) 'large' (%)	Score 4 (53–84) 'very large' (%)
Current severity of AE per POEM	(Almost) clear *n* = 195	67.2	26.2	6.7	0
	Mild *n* = 453	54.3	29.8	13.9	2.0
	Moderate *n* = 359	29.2	27.0	34.3	9.5
	Severe *n* = 140	16.4	21.4	32.9	29.3
	Very severe *n* = 42	16.7	16.7	16.7	50.0

AE Atopic eczema, *AESEC* Atopic Eczema Score of Emotional Consequences, *POEM* Patient Oriented Eczema Measure

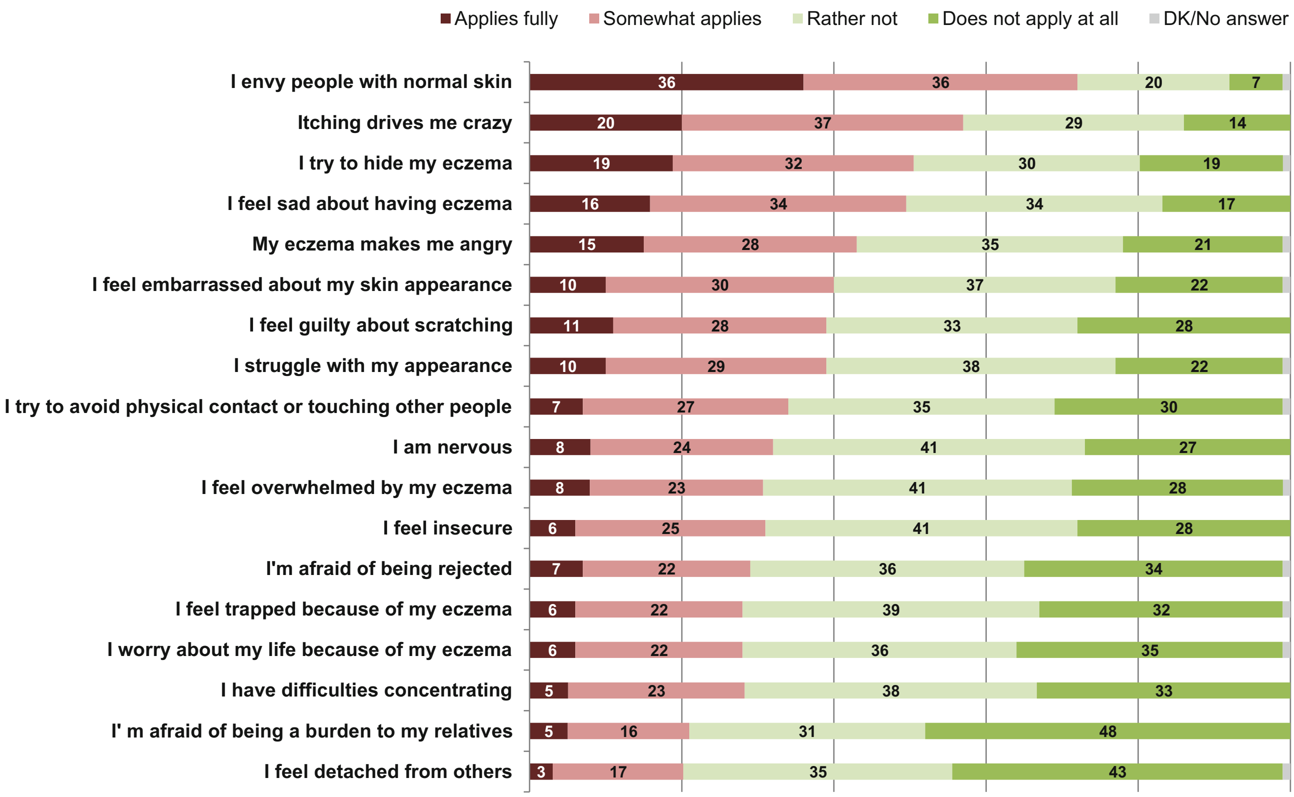

Fig. 3 Rating of AESEC in detail I—negative items sorted

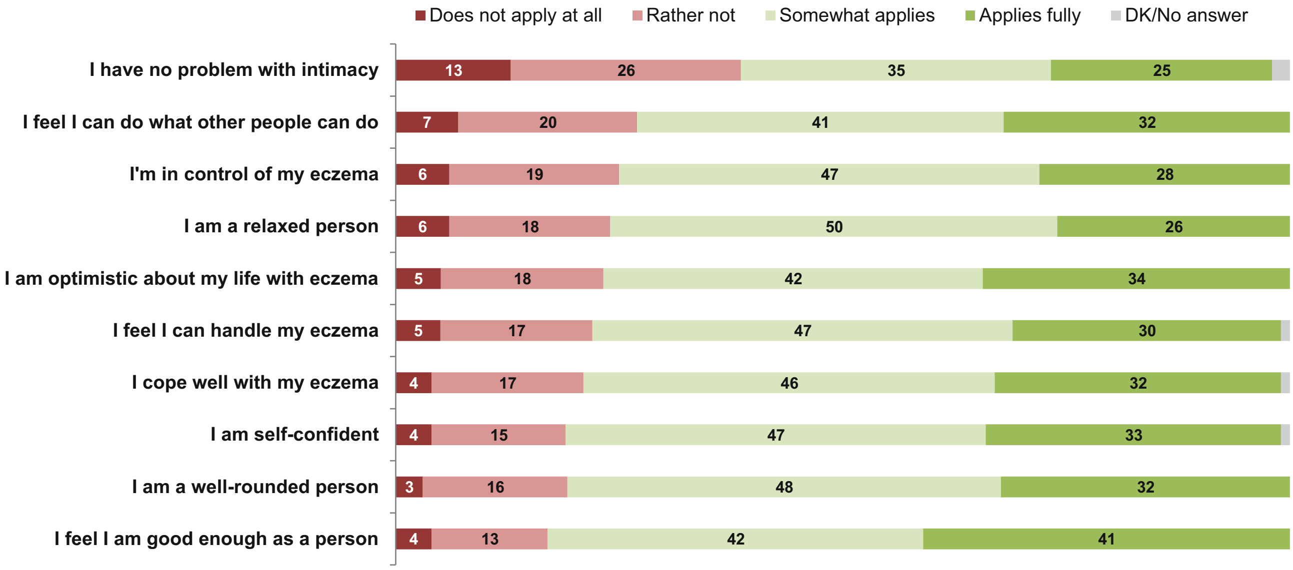

Fig. 4 Rating of AESEC in detail II—positive items sorted

burden of people living with AE and what typically distresses them in daily life. However, the method of telephone interviewing might have also led to interviewer, recall and social desirability bias. Patients might have understated their negative feelings with an unknown interviewer. A further limitation might be the inclusion of people with AE whose disease cannot be adequately controlled with topical treatment, focusing therefore on people with a more severe form of AE. Looking at the severity of the AE symptoms at the time of participation measured with POEM, it is clear that although including participants who are innately moderately to severely affected, there is a variance from almost no symptoms to severe symptoms. Whether this effect is due to systemic immunomodulatory treatment or phototherapy—or a short course of oral corticosteroids—cannot be established based on the data, and is beyond the scope of the study. Yet

Table 7 AESEC Questionnaire with 28 items and results[a]

No	Statement	Applies fully (%)	Somewhat applies (%)	Rather not (%)	Does not apply at all (%)	DK/No answer[b] (%)
Q01	I feel detached from others	3	17	35	43	1
Q02	I try to hide my eczema	19	32	30	19	1
Q03	I am self-confident	33	47	15	4	1
Q04	I am nervous	8	24	41	27	0
Q05	I envy people with normal skin	36	36	20	7	1
Q06	I feel I can handle my eczema	30	47	17	5	1
Q07	I feel overwhelmed by my eczema	8	23	41	28	1
Q08	I am optimistic about my life with eczema	34	42	18	5	0
Q09	I try to avoid physical contact or touching other people	7	27	35	30	1
Q10	I struggle with my appearance	10	29	38	22	1
Q11	I am a relaxed person	26	50	18	6	0
Q12	My eczema makes me angry	15	28	35	21	1
Q13	I'm afraid of being rejected	7	22	36	34	1
Q14	I am a well-rounded person	32	48	16	3	0
Q15	I feel guilty about scratching	11	28	33	28	0
Q16	I have difficulties concentrating	5	23	38	33	0
Q17	I'm in control of my eczema	28	47	19	6	0
Q18	I feel sad about having eczema	16	34	34	17	0
Q19	I feel I can do what other people can do	32	41	20	7	0
Q20	I worry about my life because of my eczema	6	22	36	35	1
Q21	I feel embarrassed about my skin appearance	10	30	37	22	1
Q22	I have no problem with intimacy	25	35	26	13	2
Q23	I feel insecure	6	25	41	28	0
Q24	I cope well with my eczema	32	46	17	4	1
Q25	I feel trapped because of my eczema	6	22	39	32	1
Q26	I feel I am good enough as a person	41	42	13	4	0
Q27	I'm afraid of being a burden to my relatives	5	16	31	48	0
Q28	Itching drives me crazy	20	37	29	14	0

DK don't know
[a] Percentages were rounded to whole numbers
[b] Although per design this answer category was not defined, it was inevitable when using telephone interviews in case people could or would not answer
AESEC Atopic Eczema Score of Emotional Consequences

this variance enabled us to measure emotional consequences of having a more severe form of AE whilst covering the whole spectrum of disease severity.

There are also some limitations regarding the methodology. It was not feasible within this study to do a 'test–retest procedure' to further examine the reliability of the AESEC questionnaire. This was due to the large sample and the chosen method of Computer Assisted Telephone Interview. Nor could we therefore investigate the responsiveness of the questionnaire. Both aspects (test–retest and responsiveness) could be subjects for further studies. There is also a limitation with the method of categorizing the AESEC scores into no/small, moderate, large or very large impact. Ideally one would use the methodology that was applied to DLQI [39] and POEM [27], yet the anchors in this study (POEM, DLQI, self-assessed severity) were not suitable to be able to do so. Although we are of the opinion we found the best cut-off values, it might be valuable to address this in another study.

In conclusion, AESEC is a new tool for assessing the emotional consequences of living with AE. AESEC could prove useful in the full assessment of living with AE beyond objective symptoms and time-specific, general quality of life, which becomes more and more essential, especially in times of several new systemic treatment options for AE on the rise.

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Conflict of interest B.W.M. Arents, U. Mensing, I.A. Seitz, N. Wettemann, A. H. Fink-Wagner, G. de Carlo, A. Zink and J. Ring declare that they have no competing interests.

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