

Infants' Dermatitis Quality of Life Index: a decade of experience of validation and clinical application

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Summary

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Accepted for publication

14 May 2013

Funding sources

None.

Conflicts of interest

A.Y.F. is joint copyright owner of the IDQoL.
Cardiff University gains some income from the use of the IDQoL.

DOI 10.1111/bjd.12563

The Infants' Dermatitis Quality of Life Index (IDQoL) is a questionnaire completed by parents to assess the impact of atopic dermatitis on the quality of life of infants aged 0–3 years. The aim was to review all clinical and psychometric data on the use of the IDQoL from its inception in 2001 until November 2012, to serve as a single reference source. A literature search was carried out using Medline, PubMed, EBSCOhost, Science Direct and Google Scholar. Articles and abstracts that described the clinical use of the IDQoL and those that investigated its psychometric properties were included. Articles not in English were excluded. Fifty-one publications were identified, of which 46 fulfilled the inclusion criteria. IDQoL data relating to psychometric, descriptive and clinical practice research, drug trials and therapeutic interventions were extracted. The IDQoL has been translated into 21 languages and used in 18 countries, including two multinational studies. Thirty-one studies demonstrated its psychometric properties, such as test–retest reliability, internal consistency, validity, responsiveness to change and interpretability. No studies investigated dimensionality, carried out factor analysis or described the minimal clinically important difference of the tool. Eight studies used the IDQoL to assess the effectiveness of therapeutic interventions such as education programmes, consultations and wet-wrap therapy, while seven studies described the use of IDQoL in topical interventions. When deciding whether to use the IDQoL, researchers and clinicians should consider the validation data, the relevant comparative clinical data available and the potential burden on the respondents.

What's already known about this topic?

- The quality of life of infants may be severely affected by atopic dermatitis.
- As infants cannot answer questions, proxy methods are needed to measure their life quality.
- The Infants' Dermatitis Quality of Life Index (IDQoL) has been widely used for such assessment.

What does this study add?

- The IDQoL has been used in 46 published studies in 18 countries. This review collates the scattered data about the wide use of the IDQoL in clinical and psychometric studies.
- Seven studies used the IDQoL in assessment of topical therapy and eight in assessment of other treatment interventions.
- Test–retest reliability, internal consistency, validity, responsiveness to change and interpretability of the IDQoL have been reported across 31 studies.

Atopic dermatitis (AD) is a common disease that affects the quality of life (QoL) of patients and their families.¹ It occurs in infants and young children at a vital stage in their social and emotional development.² It is well known to dermatologists that the lives of infants with AD are disrupted by discomfort, scratching, poor sleep patterns, treatment of the skin and other changes to normal family life.³ As this is such an important part of the experience of having the disease, it would be helpful to have a reliable measurement method.⁴ QoL measures usually rely on self-assessment by the affected person, but for infants a proxy measure is required, using the parents to provide the assessment of how their child's life is affected by AD. The Infants' Dermatitis Quality of Life Index (IDQoL) is a questionnaire completed by parents to assess the impact of AD on the QoL of infants aged 0–3 years.³ The questions in the IDQoL were based on the experiences of parents of children with AD.³

A review of 382 randomized controlled trials of patients suffering from AD showed that 67 studies used QoL measures; the IDQoL was used in 12% of these and was the fourth most frequently used QoL measure.⁵

Since its development, the use of the IDQoL has revealed many aspects of its validation, but these are scattered throughout different publications. The aim of this review was to identify and consolidate the scattered data about clinical aspects and validation of the IDQoL into a single readily available reference source to allow potential users of the IDQoL to decide whether the instrument is appropriate for their needs, and to identify areas of validation that require further investigation.

Infants' Dermatitis Quality of Life Index

The IDQoL, first described in 2001,³ was designed to measure the impact of having AD on the QoL of an infant under the age of 4 years. The IDQoL is completed by the child's parent or carer. It consists of 10 questions including: itching and scratching; mood of the child; how long it takes for the child to sleep; has the eczema interfered with their playing, swimming or participation in other family activities; problems during mealtimes; problems caused by treatment; level of comfort while dressing or undressing the child; and problems during bath times. Each question asks about the impact over the previous week and is scored a minimum of zero and a maximum of three. The score is calculated by summing the scores of individual items, leading to a total between zero (no impact) and 30 (maximum impact). There is an additional separate question regarding the severity of the dermatitis, which is scored from none to extremely severe (0–4). This item is not included in the overall IDQoL score.

The IDQoL has been used in many different language versions in various countries. However, it should be noted that cultural influences and the varying appropriateness of the questions in different cultures may result in the scores having different meanings in different countries.

Methods

All articles describing the clinical use of the IDQoL, and its psychometric properties, from its publication in 2001 to November 2012, were identified using PubMed, Medline, Google Scholar, Science Direct and EBSCOhost, with the search terms 'IDQoL' and 'Infants' Dermatitis Quality of Life'. Both articles and abstracts were included, but those in languages other than English were excluded.

Data extracted concerning psychometric properties included: dimensionality of the measure, factor structure, test–retest reliability, internal consistency, reliability, validation against other measures, interpretability or clinical meaningfulness of the scores and of score change, sensitivity to change, specificity compared with healthy infants, translations, cross-cultural adaptations and special statistical tests used. Study setting and sample size were recorded for every study.

Data extracted concerning clinical studies included: the primary aim of the study, intervention whether topical or non-pharmacological, epidemiological surveys, country, language, skin condition, study design and setting, duration of condition, sample size, patient age and sex, disease severity assessment, intervention, mean/median IDQoL scores for both the patients and controls at baseline and postintervention, final outcome of the study and special statistics used. The data were cross-checked twice with the original articles to ensure accuracy.

Results

Fifty-one publications were identified that used the IDQoL; 46 (30 articles and 16 abstracts) fulfilled the inclusion criteria.

In one report⁶ IDQoL and Children's Dermatitis Life Quality Index data were apparently combined to give an overall score. These data may not be valid and have therefore been excluded from the review. Two articles^{7,8} reported the same IDQoL data and therefore only the information from the initial article⁷ was included. Identical data concerning a pilot study are reported in four different abstracts^{9–12} and therefore only the latest abstract was included.¹² An article by Eichenfield *et al.*¹³ describes the same study reported by Msika *et al.*,¹⁴ and thus only the original study is reported.¹⁴

Psychometric data

Dimensionality and factor structure

No studies demonstrated the dimensionality or factor analysis of the IDQoL.

Test–retest and internal consistency reliability

The test–retest reliability of the IDQoL was assessed in three studies^{3,15,16} (Table 1). Two studies^{3,16} reported Spearman's rank correlation, $r \geq 0.89$, two^{15,16} showed intraclass correlation coefficient ≥ 0.89 and one¹⁵ reported weighted κ coefficients

Table 1 Test–retest and internal consistency reliability studies

Study	Clinical setting	Country	n	Method used	Results
Lewis-Jones ³	Dermatology clinic	U.K.	72	Spearman's rank correlation	$r = 0.91$
Baranzoni ¹⁵	Hospital	Italy	21	ICC	ICC = 0.95
				Weighted kappa coefficients	$\kappa = 0.63\text{--}1.00$
				Internal consistency: Cronbach α	$\alpha > 0.7$
van Valburg ¹⁶	General practice	The Netherlands	66	Spearman's rank correlation	$r = 0.89$
				ICC	ICC = 0.89
Neri ¹⁷	Hospital, postal	Italy	102	Cronbach α	$\alpha = 0.89$

ICC, intraclass correlation coefficient.

ranging from 0.63 to 1.00, demonstrating good reliability. Two studies assessing the internal consistency of the IDQoL demonstrated Cronbach $\alpha > 0.7$ ¹⁵ and 0.89.¹⁷ These four studies were carried out in hospital settings in the U.K. and Italy, and in a general practice setting in the Netherlands.

Validation against other measures

Eighteen studies described the use of the IDQoL in parallel with other instruments, allowing assessment of correlation with other measures, for example demonstrating the construct validity of the IDQoL (Table 2).^{3,14,15,17–31} The comparator instruments and the number of studies using each measure were: Scoring Atopic Dermatitis (SCORAD), seven studies^{14,21,23,27–30} (to assess the severity of the AD objectively); the Dermatitis Family Index, seven studies^{3,15,18–21,27} (measures the impact of a child's AD on the family); Eczema Area and Severity Index, three studies^{22,26,31}; clinical severity assessed by parents, two studies^{3,20}; Rajka and Langeland AD severity score, two studies^{21,30}; and Childhood Atopic Dermatitis Impact Scale, one study.¹⁷ SCORAD is the most commonly used and probably the best validated measure of AD disease activity, mainly based on signs but also including two symptom questions relating to pruritus and sleep. Of the seven studies in which both SCORAD and IDQoL were used,^{14,21,23,27–30} most demonstrated reasonable correlation. The 18 studies describing aspects of cross-validation against other measures were carried out in 10 different countries, raising the likelihood that the meaning and completion of both the IDQoL and the comparator measures may have been influenced by differing cultural interpretation and lack of cross-cultural adaptation.

Interpretability or clinical meaningfulness of the scores

Interpretability is the ability to assign an understandable meaning to a score or change in score of an instrument. The minimum clinically important difference (MCID) for IDQoL scores has not been described and there is no validated score-banding system to give meaning to IDQoL scores. However, in one publication³² nonvalidated score bands were used to interpret the data. The same authors used these nonvalidated score bands in another study,³³ as did different authors in a

further study.³⁴ This score-banding system appeared to have been arbitrarily based on the validated Dermatology Life Quality Index banding system.³⁵

Sensitivity to change

Nineteen publications described the sensitivity of the IDQoL to change following intervention (Table 3).^{3,7,14,15,18,20,23,29,31,33,36–44} These studies took place in 11 countries, with patient numbers ranging from 10 to 203. The reported mean change in scores following a variety of interventions ranged from 0.46 to 8.1, median 3.7. As the MCID for the IDQoL has not been calculated, it is not possible to interpret these score changes directly in terms of clinically meaningful change.

Specificity – compared with healthy infants

In an observational study of 117 children with AD and 396 children with no skin diseases, there was a significant difference between the mean scores for the two groups, with the mean IDQoL score in the AD group being 9.2 (range 1–19).⁴⁵ In a study of 55 infants with AD and 79 infants without skin disease, the mean IDQoL scores of the infants with AD at the ages of 6, 12 and 24 months were 4.15 (SD 2.96), 3.89 (SD 3.62) and 3.23 (SD 2.71), respectively. In the control group the mean modified IDQoL scores for the healthy infants were 2.11 (SD 1.96), 2.05 (SD 2.12) and 2.50 (SD 2.94) at 6, 12 and 24 months, respectively.³⁴

Descriptive and clinical studies

Translations, cross-cultural adaptations and use in other countries

There have been validated translations of the IDQoL into 21 languages (Table 4) and one description of cross-cultural adaptation in Ukrainian.⁴⁰ The IDQoL has been used in several parts of Europe and four other continents, demonstrating its ability to be used in other cultures, but this does not provide evidence of cultural appropriateness. The IDQoL has been used in 18 countries (Table 4).^{3,7,12,15–34,36–38,40–52} There have been two international studies using the IDQoL: a therapeutic

Table 2 Correlation of the Infants' Dermatitis Quality of Life Index (IDQoL) with other measures

Study	Clinical setting	Country	n	Validity type	Methods	Results
Lewis-Jones ³	Clinic	U.K.	89	Construct (convergent): correlation between IDQoL and DFI Construct (convergent): correlation between IDQoL and clinical severity as assessed by parents	Spearman's rank correlation coefficient	$r = 0.87$ (95% CI 0.82–0.92) $r = 0.58$ (95% CI 0.32–0.64)
Chinn ¹⁸	Clinic	U.K.	115 113	Construct (convergent): correlation between IDQoL and DFI Construct (convergent): correlation between IDQoL and severity of eczema	Spearman's rank correlation coefficient Spearman's rank correlation coefficient	$r = 0.86$ ($P < 0.001$) $r = 0.59$
Scalone ^{19,a} Beattie ²⁰	Multicentre Clinic	Italy U.K.	39 203	Construct: correlation between IDQoL and DFI Construct (convergent): correlation between IDQoL and DFI Construct (convergent): correlation between IDQoL and clinical severity as assessed by parents	NR Spearman's rank correlation coefficient	$P < 0.0001$ $r = 0.776$ $r = 0.636$
Baranzoni ¹⁵	Hospital	Italy	21	Construct (convergent): correlation between IDQoL and DFI	NR	High and statistically significant correlation
Gånemo ²¹	Hospital	Sweden	28	Construct: correlation between IDQoL and DFI Correlation between IDQoL and Rajka & Langland eczema severity score	Spearman's rank correlation coefficient	$r = 0.78$ ($P < 0.01$) $r = 0.48$ ($P < 0.05$)
Park ²² Msika ¹⁴	Outpatient Multicentre	South Korea France	101 86	Correlation between IDQoL and SCORAD Construct (convergent): correlation between IDQoL and EASI Correlation between IDQoL and SCORAD	Linear regression Pearson's linear correlation coefficient	$r = 0.30$ ($P > 0.05$) $R^2 = 0.126$ Significant correlation after 21 days of treatment ($P < 0.01$)
Palmer ²³	Postal, clinical	Australia	30	Construct (convergent): correlation between IDQoL and observed SCORAD at day 0 and day 24 of study	Pearson's product-moment correlation coefficient	$r = 0.41$, day 0; $r = 0.71$, day 24
Ahmad ^{24,a} Chernyshov ²⁵	Clinic NR	Ireland Ukraine	51 21	Construct: correlation between QoL scores and severity Construct: correlation between IDQoL scores and parent's sex	NR Spearman's rank correlation coefficient	Strong positive correlation No significant differences between mother's and father's assessment of separate items of the IDQoL
Alvarenga ²⁶ Monti ^{27,a}	NR Hospital	Brazil Italy	86 37	Construct: correlation between IDQoL and EASI Construct (convergent): correlation between IDQoL and SCORAD	Pearson's correlation coefficient Pearson's correlation coefficient	$r = 0.219$ $r = 0.401$ ($P = 0.001$)
Chernyshov ²⁸ Cho ²⁹	NR NR	Ukraine South Korea	50 45	Correlation between IDQoL and DFI Construct (convergent): correlation between IDQoL and SCORAD Construct (convergent): correlation between IDQoL and objective SCORAD	Spearman's rank correlation coefficient NR	$r = 0.755$ ($P \leq 0.0001$) $r = 0.35$ (average) $r = 0.062$
Kim ³⁰	Clinical	South Korea	71	Construct: correlation between IDQoL and Rajka & Langland score	Spearman's rank order correlation coefficient	$r = 0.501$
Neri ¹⁷	Hospital, postal	Italy	102	Correlation between IDQoL and SCORAD Concurrent validity: correlation between IDQoL and CADIS (long and short versions)	Spearman's rank order correlation	$r = 0.596$ $r = 0.40$ – 0.75 (long CADIS); $r = 0.32$ – 0.74 (33-item CADIS)
Wu ³¹	Hospital	China	55	Construct (convergent): correlation between IDQoL and EASI	Spearman's rank correlation coefficient	$r = 0.826$

DFI, Dermatitis Family Index; CI, confidence interval; SCORAD, Scoring Atopic Dermatitis; EASI, Eczema Area and Severity Index; NR, not reported; CADIS, Childhood Atopic Dermatitis Impact Scale.
^aReference to an abstract.

Table 3 Studies demonstrating Infants' Dermatitis Quality of Life Index (IDQoL) sensitivity to change

Study	Clinical setting	Country	n	Method used	Results	Comments
Lewis-Jones ³	Clinic	U.K.	25	Wilcoxon signed-rank test	Before 10.20 ± 6.76, after 7.32 ± 5.76	Study conducted to assess the validity of IDQoL. P = 0.0473
Chim ¹⁸	Clinic	U.K.	115	NR	Change from baseline: patient 0.46 ± 5.1, control: -0.71 ± 4.4	No significant improvement with intervention at 4 or 12 weeks
Beattie ³⁶	NR	U.K.	19	NR	Group 1: before 10.8 (7.6–14), after 6.3 (2.2–10.3). Group 2: before 12.3 (7–17.7), after: 4.2 (3–5.4)	95% CI
Grad ^{37,a}	NR	U.S.A.	203	NR	5.13 to 4.12* in 3 months	
Beattie ²⁰	Hospital clinic	U.K.	50	Wilcoxon matched-pairs signed-rank test	Median IDQoL scores fell from 8 ± 5.92 (2–25) to 5 ± 5.92 (2–5.5). * Mean IDQoL scores fell from 9.74 to 6.06*	Confirms sensitivity to clinical change from the parents' perspective. 95% CI
Grillo ³⁸	Hospital medical centre	Australia	38	t-test	Patients: baseline 11 ± 8.29, week 12: 6.91 ± 5. Controls: baseline 8.63 ± 4.32, week 12: 5.33 ± 3.02	
Baranzoni ¹⁵	Hospital	Italy	21	NR	Median IDQoL score = 9	IDQoL administered twice in stable disease, scores similar
Grimalt ³⁹	NR	France, Spain	173	t-test	Improvement in QoL from baseline to 6 weeks: intervention 42%, control 7.5%	
Chernyshov ⁴⁰	NR	Ukraine	60	NR	Improvement in QoL using Trixera emollient cream	
Msika ⁴⁴	Multicentre	France	86	NR	Improvement in QoL with SOD cream: 65–75% vs. baseline	Better QoL using emollient with 2% SOD than with TCS alone
Palmer ²³	Postal, clinic	Australia	30	Mixed between- and within-subject ANOVA	Day 0: intervention group 10.9 ± 5.3, control group 8.4 ± 3.5. Day 23: intervention group 5.9 ± 4.9, control group 5.1 ± 3.4	
Shaw ⁴¹	Clinic	U.S.A.	66	t-test	Patients: baseline 8.88 ± 5.25, 3 months improved by 31% ± 59.28. Controls: baseline 8.05 ± 5.98, 3 months improved by 27% ± 54.4	
Kubota ⁴²	Clinic	Japan	10	Wilcoxon signed-rank test	Baseline 6.40, week 6: 2.20, week 12: 2.75	
Ricci ³³	NR	Italy	30	NR	Baseline 6.85, final 4.25	Useful in long-term management of AD with medical treatment
Schuttelaar ⁷	Outpatient clinic	Netherlands	80	t-test	Mean change from baseline to 12 months: dermatologist -6.5 ± 6.6, nurse practitioner -4.9 ± 5.5; (-6.8 to -3)	Dermatologist -14.2 to -8.9,* nurse practitioner 95% CI*
De Belilovsky ⁴³	NR	France	80	NR	IDQoL improved similarly by 65%/67% in group A and 72%/75% in group B at day 21	
Gore ⁴⁴	Clinical	U.K.	137	ANOVA	Baseline: patient 5.7–7.2, control 6.5. After visit seven: patient 1.3–1.6, control 1.3	95% CI
Cho ²⁹	NR	South Korea	45	NR	IDQoL: baseline 9.0; second interview (after at least 12 months) 6.0	The changes of SCORAD were linearly related to the changes of IDQoL
Wu ³¹	Hospital, dermatology and paediatric departments	China	55	Mann-Whitney U-test	Baseline 15 ± 8, final 5 ± 2	

NR, not reported; CI, confidence interval; QoL, quality of life; SOD, sunflower oleodisillate; TCS, topical corticosteroid; AD, atopic dermatitis. *Reference to an abstract. *P ≤ 0.0001.

Table 4 Language translations of the Infants' Dermatitis Quality of Life Index (IDQoL) and countries in which it is used

Language	Country	References
NS	China	31
NS	Cuba	45 ^a
Czech	Czech Republic	46–48
Danish	Denmark	46, 50
Dutch	The Netherlands	7, 16, 46
Dutch (Belgium)	Belgium	46
English	Australia	23, 38
English	Ireland	24 ^a
English	U.K.	3, 18, 20, 36, 44, 46, 51 ^a
English	U.S.A.	1, 37, ^a 41
Finnish	Finland	34, 46
French	France	12, ^a 14, 43, 46
German		46
Greek		46
Hungarian		46
Italian	Italy	15, 17, 19, ^a 27, ^a 32, 33, 46
NS	Japan	42
NS	South Korea	22, 29, 30
Norwegian		46
Persian		46
Polish		46
Portuguese		46
Portuguese (Brazil)	Brazil	26, 46
Spanish		46
Swedish	Sweden	21, 46, 49
Turkish		46
Ukrainian	Ukraine	25, 28, 40, 46, 47, 52
Yoruba		46

NS, not stated. Copies of the above validated language translations of the IDQoL are available from the Cardiff University Department of Dermatology website.⁴⁶ Although the IDQoL has been used in Japan,⁴² China³¹ and South Korea,^{22,29,30} we do not have access to these translations. ^aReference to an abstract.

intervention study in France and Spain,³⁹ and a comparative study between Ukraine and the Czech Republic.⁴⁷

Topical drug interventions

The IDQoL has been used in seven studies of pharmacological interventions with topical applications.^{14,31,37,39,40,42,43} The topical drug studies were of pimecrolimus,³⁷ emollients used for steroid sparing,³⁹ Trixera emollient cream,⁴⁰ sequential tacrolimus and topical corticosteroids,⁴² sunflower oleodistillate^{14,43} and 15-(R/S)-methyl-lipoxin A₄.³¹ The actual IDQoL scores were reported in only two of these studies.^{31,42} In another two reports,^{14,43} only the percentage change from baseline was reported, and in the other three studies^{37,39,40} there were no IDQoL data, but a descriptive account of improvement was given. Five studies^{14,31,37,40,43} were stated to have shown improvement in scores following intervention, but statistical significance was generally not reported.

Other nonpharmacological interventions

Eight articles reported the outcome of nonpharmacological interventions such as wet-wrap therapy,³⁶ educational programmes,^{33,38,41} consultations with dermatologists and nurse practitioners,^{7,18,20} and adjunct therapy with *Lactobacillus paracasei* and *Bifidobacterium lactis*⁴⁴ (Table 5). In six of the eight reports,^{7,20,33,36,38,44} mean IDQoL scores were given, and in two reports^{18,41} the changes from baseline scores were given, with the baseline scores also given in one of these.⁴¹ A notable finding was that education reduces the severity of AD and improves QoL.³⁸

Epidemiological surveys and other uses

A cross-sectional study⁴⁷ demonstrated that the assessment of the IDQoL by parents of patients with AD in Ukraine (mean IDQoL 7.62, SD 4.84) was similar to that in the Czech Republic (mean 7.78, SD 5.48). Another cross-sectional study⁴⁸ evaluated the QoL of Czech children with AD in different age groups, and of their families (mean IDQoL 8.18, SD 5.84, *n* = 120).

A pilot study of 36 infants with AD reported a mean IDQoL score of 14.47 (SD 3.37).¹² Furthermore, in a study of 45 children with AD, the severity of AD was described in relation to the scores of the IDQoL.³² Some 78% of children with mild AD had normal QoL, and all of the patients with highly impaired QoL suffered from severe AD.³² Although the IDQoL was specifically designed for use in dermatitis, it has also been used in psoriasis.⁴⁹

Discussion

Atopic dermatitis in infants affects not only the children but also their parents and siblings. The family's life is altered, as eating out, dressing, playing, owning pets and going on holidays is affected, described by parents as 'a general burden of extra care'.⁵³ Lack of information on the condition and its management increases parental anxiety and social isolation. Sleep deprivation causes tiredness, mood changes and impaired functioning of the child and family, particularly at school and work. The extent of the impact of disease on QoL of infants has been reviewed.⁵⁴

The inability to speak, immature and unsophisticated communication skills, and lack of concentration are all obvious major difficulties in assessing QoL in infants. However, even young infants can communicate likes and dislikes, and parents are able to interpret this by their behaviour and changes in mood. Parents or caregivers may provide valuable information based on their judgement of a child's health status and QoL.⁵⁵

Objective clinical measures alone cannot be used to describe AD as experienced by a patient, as they do not take into account the impairment of QoL that may occur. QoL assessment has become important as an additional outcome measure for clinical trials, as well as for informing health administrators and policy makers. The use of instruments to measure

Table 5 Nonpharmacological interventions using the Infants' Dermatitis Quality of Life Index (IDQoL)

Study	Therapeutic intervention	n	Mean IDQoL score		Remarks
			Before	After	
Chim ¹⁸	Single nurse consultation	97	Not reported	Change from baseline: patient 0.46 ± 5.1, control -0.71 ± 4.4	No significant improvement with intervention at 4 or 12 weeks
Beattie ³⁶	Wet-wrap therapy	19	Patient 10.8, control 12.3	Patient 6.3, control 4.2	Failed to show any benefit
Beattie ²⁰	Consultation with dermatology team	50	9.74 ± 5.92	6.06 ± 5.92	Beneficial to both patient and parent
Grillo ³⁸	Educational programme (2 h workshop)	38	Patient 11, control 8.63	Patient 6.91, control 5.33	Education decreases severity of eczema
Shaw ⁴¹	Education programme (15 min personal time)	66	Patient 8.88 ± 5.25, control 8.05 ± 5.98	Patient 31% ± 59%, control 27% ± 54%	No significant difference between patients and controls
Ricci ³³	Educational programme (six meetings each of 90 min)	30	6.85	4.25	Useful in long-term management of atopic dermatitis with medical treatment
Schuttelaar ⁷	Nurse practitioner (NP) vs. dermatologist (D)	80	NP 10.7, D 11.6	NP 5.7, D 5.6	Care from NP more satisfying than from D
Gore ⁴⁴	<i>Lactobacillus paracasei</i> and <i>Bifidobacterium lactis</i>	137	Patient 5.7-7.2, control 6.5	Patient 1.3-1.6 (after visit 7), control 1.3 (after visit 7)	No benefit when given as adjunct to basic topical treatment

QoL, giving weight to patients' views, has the potential to encourage patients' involvement in their treatment regime. The IDQoL was developed as a method to assess the QoL in infants with AD, to be used in conjunction with other instruments that measure the disease severity 'objectively'. It is to be expected that the impact on an infant's life would be related to the severity of the AD, especially when the IDQoL is completed by parents, whose replies may be influenced by their perception of the activity of the disease. In addition, the most widely used formal method of measuring AD in clinical studies, SCORAD, contains two questions related to pruritus and sleep, also covered by IDQoL, thereby increasing the likelihood of the scores being correlated. As parents or carers may have differing views of the impairment of the infant's QoL, it is important that the same individual completes the questionnaire on consecutive occasions.

This review has identified the wide range of values of IDQoL reported in different studies. This might partly be explained by differences in study selection criteria. However, as an infant with AD presumably experiences broadly similar effects on its life wherever the child may be, it might have been expected that the reported score ranges would be similar. The differences may be explained partly by differing cultural influences on how the forms are interpreted and completed. Although all of the translations described have been confirmed as accurate by an iterative process of forward and backward translation, only one translation⁴⁰ underwent cultural adaptation and validation. Ideally, full cultural adaptation should be carried out when a QoL measure is used in another culture. Even when full cultural adaptation has taken place, score comparability between cultures does not necessarily follow. Scores from QoL measures such as the IDQoL cannot therefore necessarily be compared between countries. However, the use of the IDQoL in 18 countries demonstrates the extent of cross-cultural experience with the translated versions and indicates widespread international recognition in dermatology of the importance of attempting to measure patients' QoL, even in infants.

This review has highlighted several positive aspects of the psychometric performance of the IDQoL, for example the studies demonstrating specificity when used in infants with disease compared with healthy infants give confidence that the IDQoL questions are able to differentiate between infants with AD and infants with normal skin, in other words to support the discriminant validity of the measure. The IDQoL has shown convergent validity with a number of subjective and objective measures; however, other areas of validation have not been carried out, including testing for unidimensionality or factor analysis. The concept of MCID describes the smallest difference in score of a measure that patients perceive as beneficial, and is usually applied to directly reported patient outcomes. However, it may also be applied to proxy measures.^{56,57} It would be helpful if such information were available for the IDQoL (a proxy measure usually completed by the patient's parent), as knowledge of the MCID allows interpretation of the magnitude of score change over time.

The development of a score-banding system has not been carried out; this is another area that requires further investigation. A study to validate a score-banding system for the IDQoL needs to be conducted, and the application of nonvalidated score-banding systems should be discouraged. Test–retest reliability and internal consistency are areas that need further investigation for all cross-cultural adaptations of the IDQoL. Most studies used the IDQoL at only a short interval after intervention, and so there is no experience reported of using the IDQoL to measure impact over the long term. These various attributes of the IDQoL should be investigated further.

The IDQoL was the first attempt to measure the impact of AD on the lives of infants, and thus previously there was a lack of a 'gold standard' for comparison. However, there are now several other QoL instruments that could be used to assess QoL in infants. The Infant and Toddler Quality of Life Questionnaire⁵⁸ is designed for use in children aged from 2 months to 5 years. The short form has 47 items that are not specific to AD and can be used across all of medicine. In the development of the Childhood Impact of Atopic Dermatitis (CIAD) questionnaire,⁵⁹ the challenge of addressing cultural differences was met by using an outcome measure with different sets of items in each language. The CIAD consists of two scales, one measuring the impact of AD on the life of the carer, and the other on the life of the infant. The need for an appropriate validated questionnaire to measure the impact of skin disease other than AD on the lives of infants was highlighted by use of the IDQoL in three patients with psoriasis.⁴⁹ As the development and validation of the IDQoL were confined to the effects of AD, it is inappropriate to use the IDQoL in diseases other than AD.

There were a number of weaknesses in the data provided in several of the publications reviewed. For example, baseline or final scores were omitted in some, while statistical significance or confidence intervals were not reported in others. Sometimes the raw figures for mean or median scores were omitted, with only a percentage change being reported. This highlights a frequent problem of inconsistency of reporting of QoL data, which could be improved if there were minimum standards for reporting QoL data agreed and policed by editors. As the IDQoL scale is ordinal, nonparametric statistical tests should be used for data analysis, and it is inappropriate to use parametric tests. There is no reason to assume that data collected with the IDQoL are likely to be distributed normally. The most frequently used tests were indeed nonparametric. These included the use of Spearman rank correlation, the Mann–Whitney U-test, linear regression and the Wilcoxon signed-rank test. However, three studies^{7,38,41} used the t-test, four studies^{14,23,26,27} used Pearson's correlation coefficients and two studies^{15,16} used the intraclass correlation coefficient – all parametric tests. In several studies it was not clear which statistical methodology was applied.

In conclusion, this review has collated and concisely presented all published aspects of the IDQoL to date. This will allow potential users of the index to make an informed decision regarding the use of the IDQoL and the interpretation of IDQoL data.

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