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## Quality of Life impact of childhood skin conditions measured using the Children's Dermatology Life Quality Index (CDLQI): a meta-analysis

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### Abstract

**Background:** The Children's Dermatology Life Quality Index (CDLQI) is the most widely used instrument for measuring the impact of skin disease on quality of life (QoL) in children.

**Objective:** Provide a meta-analysis of all published quality of life (QoL) scores for a range of childhood skin conditions.

**Methods:** Studies using the Children's Dermatology Life Quality Index (CDLQI) questionnaire to measure QoL in skin conditions were identified by searching Medline and Embase from January 1995 (CDLQI creation) to December 2014. Studies were grouped according to condition and baseline scores were combined using meta-analysis.

**Results:** 67 studies using the CDLQI met the inclusion criteria. The overall estimated CDLQI scores for conditions reported more than once were: atopic eczema (Point Estimate 8.5 (95% CI 7.1-9.8), number of studies = 38, score range = 0-29), acne (5.3 (1.9-8.5), n=5, 0-30), alopecia (3.1 (0-7.7), n=2, 0-6), molluscum contagiosum (3.5 (0.6-6.7), n=5, 0-27), psoriasis (8.0 (3.9-12.1), n=6, 0-29), scabies

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(9.2 (0.0-20.3), n=2, 1-26), urticaria (7.1 (0-15.4), n=2, 0-22), vitiligo (6.5 (0.7-12.2), n=2, 0-20), and warts (2.9 (0-5.8), n=4, 0-16). Overall, the mean effect on QoL (weighted average CDLQI score 4.6 (95% CI 3.9 to 5.4)) for children with these conditions was small. However, many children were found to experience a very large impact on QoL (34% of children with atopic eczema, 10% with molluscum contagiosum and 1 - 5% with acne) in studies where the distributions of scores were provided.

**Conclusions:** Most skin conditions in children have a “small” mean effect on quality of life. However, the range is large and a significant proportion of children with many common skin conditions will experience a very large effect on quality of life.

## Introduction

Skin diseases can impair quality of life (QoL), sometimes causing a degree of impact similar to that of other chronic childhood conditions such as renal disease, cystic fibrosis and asthma (1). The Children’s Dermatology Life Quality Index (CDLQI) was developed to measure the impact of skin disease on QoL in children (2). The CDLQI has been used in over 102 studies (3) and is the most widely used dermatology specific instrument for measuring QoL in children (3). Score band descriptors allow interpretation of the meaning of CDLQI scores (4).

Up to now there has been no pooled summary or meta-analysis of the CDLQI scores reported in different skin conditions. Such a summary would allow users of the CDLQI to understand scores in the context of its previous use, allow comparison between different skin conditions, and utilise the rich data source that use of the CDLQI has created to further understand the impact of a range of skin conditions on QoL. Measuring the impact of skin disease on children is important for clinical, management, research and audit reasons, and can be helpful in guiding management decisions and making resource allocation decisions (1). QoL and disease severity scores can be used to inform clinical treatment guidelines. In the UK the National Institute for Health and Care Excellence uses QoL scores in the assessment of adult patients when considering biologics in the treatment of psoriasis (5). QoL questionnaires are mostly used in clinical research, rarely in routine clinical practice. However, they can be useful and are more likely to be used if the measure forms part of treatment planning (6) for skin conditions where the impact on QoL may often influence treatment, such as in severe psoriasis or atopic eczema. Therefore, a summary of the overall effect of individual skin conditions upon QoL may aid treatment planning. The importance of being able to measure and understand CDLQI scores was emphasised by the finding that although in most children molluscum contagiosum causes little problems, 10% of affected children experience a very large impact on their QoL, suggesting that further efforts are needed to develop more effective management strategies for this condition(7).

This study aims to conduct a meta-analysis of published QoL (CDLQI) data for a range of childhood skin conditions.

## **Methods**

### ***Description of CDLQI***

The CDLQI has 10 questions asking about the impact of a skin disease on the life of the affected child over the last week. The topics covered include symptoms, embarrassment, friendships, clothes, playing, sports, school, bullying, sleep and impact of treatment. The CDLQI has been validated for use in children aged four to 16 years, and is available as a text or a cartoon version (2, 8). Studies which used either the text or cartoon version of the CDLQI were included: during the cartoon version validation (9) there was no significant difference in QoL scores compared to the text version, thereby allowing direct comparison between data collected by either format.

### ***CDLQI scoring algorithm***

Each response to individual questions are given a score based on standard guidelines for the CDLQI (2), the full CDLQI questionnaire can be accessed at <http://www.cardiff.ac.uk/dermatology/quality-of-life/childrens-dermatology-life-quality-index-cdlqi/>. The scoring for each question is “Very much”[Score = 3], “Quite a lot”[2], “Only a little”[1], “Not at all”[0], “Blank”[0], and Q7 – “prevented school”[3]. The 10 individual question scores are summed to provide a total CDLQI score; the maximum possible score is 30, indicating maximum impact on QoL.

### ***CDLQI severity scoring***

Severity stratification of the CDLQI was created following the completion of an additional global question by 472 UK children who completed the CDLQI either in clinic or by post (4) and the bands were determined following the calculation of k-coefficients. The following severity bands for CDLQI scores were subsequently created and are used in the interpretation of QoL in this paper: 0-1 = no effect on QoL, 2-6 small effect, 7-12 moderate effect, 13-18 very large effect, 19-30 extremely large effect.

### ***Search Strategy***

A systematic search of bibliographical databases was carried out using a predefined search strategy (described below). Articles were also identified from citations within articles and from a review (3) of CDLQI use from 1995 to 2012 (3): the CDLQI was first published in 1995.

The search terms “CDLQI” and “Children’s Dermatology Life Quality Index” were used in OVID<sup>SP</sup> to search the Medline (January 1995 to December 2014) and Embase (January 1995 to December 2014) databases (search performed 11<sup>th</sup> February 2015). The search was restricted to articles in the English language and duplicates were removed (Search terms attached as supplementary materials). PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were adhered to in the reporting of this systematic review.

### ***Inclusion and exclusion criteria***

Articles were included if they were original research papers that reported QoL using the CDLQI. We excluded studies if data were not presented at baseline in intervention studies, if mean or median CDLQI scores were not presented, or if only statistical differences between CDLQI scores between

two time points were presented. Studies were excluded where CDLQI and DLQI scores were inappropriately combined as this makes it impossible to identify actual CDLQI scores(10).

### **Data extraction**

All articles identified from the search were screened and data was extracted by one author (JO). Each article was assessed to ensure CDLQI scores were presented. Where studies met the inclusion criteria the following data were extracted and transferred to an electronic database; condition, location, setting, study design, sample size, age of subjects, CDLQI score (mean and standard deviation (s.d.) or median if s.d. not presented) and range of CDLQI scores (if presented). For intervention studies where baseline scores were given relating to separate treatment arms, both baseline scores were included within the review. Data concerning the clinical setting and study design was collected to identify any risk of bias caused by the clinical setting in which the subjects were seen.

### **Analysis**

STATA 12 was used to explore the observed differences between mean CDLQI scores. Only articles which reported mean and s.d. CDLQI scores were included in the meta-analysis. Information from articles that reported other data is given in Supplementary Table 1. The sample-weighted average effect size was calculated for individual skin conditions and overall for all of the skin conditions included within the analysis. A random-effects model was fitted to account for the variation in individual study effect size(11). The *I-squared* ( $I^2$ ) index was calculated to describe the heterogeneity by condition and overall for all conditions included within the model, the strength of evidence for heterogeneity was categorised by the following; <40% may not be important, 30-60% moderate heterogeneity, 50-90% substantial heterogeneity, and >75% considerable heterogeneity (12).

## **Results**

### **Literature search**

Our search identified 156 articles. After reviewing the abstracts of all 156 articles, 67 met the inclusion criteria (Figure 1). Within the 67 articles, CDLQI scores were given for 27 skin conditions. The following conditions were included: acne (number of articles=7), alopecia (n=2), atopic eczema (n=48), molluscum contagiosum (n=5), psoriasis (n=11), scabies (n=3), vitiligo (n=5), viral warts (n=4), and the following which were each reported once; buruli ulcer, congenital ichthyosis, ectodermal dysplasias, epidermolysis bullosa simplex, erythropoietic protoporphyria, hydroa vacciniforme, hypertrichosis, moles, naevi, neurofibromatosis 1, photosensitivity disorders, pigmentary abnormality, pityriasis rosea, scleroderma, urticaria, vascular abnormality, visible vascular and pigmentary conditions, and xeroderma pigmentosum (Table S1).

### **Study characteristics**

Of the 67 articles, the majority described case series studies of children attending a specialist dermatology centre (n=45 (67.2%)). Thirteen (19.4%) were intervention studies, six (9.0%) cohort studies and three (4.5%) cross-sectional studies. The majority of studies described QoL in children recruited in the secondary care setting (n=57, 85.1%), nine recruited children from the community

(13.4%) and one in primary care (1.5%). Over half of the articles (n=38 (56.7%)) described children from Western Europe or North America.

Most studies contained data about only one condition, however five studies, two from the UK and one each from Turkey, Hong Kong and Brazil, used the CDLQI in all children attending dermatology outpatient clinics, covering a range of skin conditions(1, 2, 13-15).

### ***CDLQI scores by condition***

The meta-analysis included combined data of 7,798 children who completed CDLQI questionnaires for 20 skin conditions. The mean CDLQI scores of all skin conditions included within the meta-analysis ranged between 3.9 to 5.4 (point estimate 4.6) (Figure 2), indicating that overall these childhood conditions have a "small" mean effect on QoL (4). However the range of scores reported for each condition (Figure 2) demonstrate that many subjects reported scores that indicate "very large" effect or "extremely large" effect on QoL, using the score band descriptors (4). The CDLQI has been mostly used for children with atopic eczema. The mean (s.d.) CDLQI scores were provided in 38 studies giving a weighted average of 7.1 to 9.8 (point estimate 8.5), suggesting that atopic eczema has a "moderate" mean effect on QoL in children (4). This also has to be placed in context of the wide range of scores reported (0 to 30), with many subjects reporting scores indicating "very large effect" or "extremely large effect".

The weighted-estimated mean CDLQI scores for skin conditions reported by more than one study were; acne (point estimate 5.3 (95% CI 1.9 to 8.5)), alopecia (3.1 (0 to 7.7)), molluscum contagiosum (3.5 (0.6 to 6.7)), psoriasis (8.0 (3.9 to 12.1)), scabies (9.2 (0.0 to 20.3)), urticaria (7.1 (0 to 15.4)), vitiligo (6.5 (0.7 to 12.2)), and warts (2.9 (0 to 5.8)). Many of these studies were based on small numbers with wide confidence intervals. There was no substantial effect of heterogeneity on the results ('I-squared' – Figure 2) either for individual skin conditions or overall for all the skin conditions included in the analysis.

Twenty articles (30%) described the range of CDLQI scores, most reporting a considerable range in QoL impairment, from between "no" effect (CDLQI score 1 or less) to some children experiencing an "extremely large" effect on QoL (CDLQI score 19 to 30). Figure 2 highlights the QoL impact severity bands (4). Six studies describing cross cultural adaptations and validation of the CDLQI were identified by Salek et al (3) and summarised in the Table 6 of their detailed review of CDLQI usage.

The distribution of QoL scores by condition was described in six studies (Table 1). Only the studies reporting molluscum contagiosum and atopic eczema used the exact validated score banding descriptors (4).

### **Discussion**

Overall the skin conditions included within this meta-analysis were found to have a "small" mean effect on QoL. However this overall conclusion gives a misleading view of the reality of the impact of skin diseases on QoL from the perspective of the health care services. The range of CDLQI scores reported for most conditions (in those 30% of studies which report them) together with stratification of severity of effect in a limited number of studies suggests that a considerable number of subjects may experience major impact, implying they could require urgent appropriate treatment. Given the

high prevalence of skin disease, even if only say 10% of children have such high scores, they still constitute a critically important cohort of patients potentially needing high resource use treatments. There is most information for the highly prevalent condition of atopic eczema, with an overall mean “moderate” effect on QoL in children. One study provided a detailed description of QoL impact for children with atopic eczema, 34% of children experienced a “very large” or “extremely large” impact on their QoL (16).

Skin conditions can impact on a child’s QoL in many ways and for those with atopic eczema the most predominate problems are scratching, sleep disturbance, mood change, problems at meal-time, dressing and bathing, playing and treatment difficulties (17). Previous research has shown atopic eczema having a great impact on QoL compared to other skin conditions, with only scabies and psoriasis having a greater impact (17). Most studies measuring impact on QoL often collect data over a fairly short time period and do not take into account the time course or curability of different conditions. For example, scabies might have a large effect on QoL at the time of completing the questionnaire but this may only be over a short time period as it is curable. Both of the two studies that measured QoL in children with scabies included within our data (2, 13) reported a high impact on QoL, however both had small sample sizes (n=6, 9) with wide confidence intervals. For psoriasis there were five studies with a wide range of CDLQI scores, leading to wide confidence intervals within the meta-analysis and describing a small to moderate average effect on QoL. Many other conditions had wide confidence intervals which suggest the impact on QoL may be a moderate or substantial effect within the meta-analysis and have a greater impact on QoL than atopic eczema.

Although a third of the articles provided the range of CDLQI scores, only six studies gave a detailed description of the proportion of children within CDLQI score descriptor bands. The most detailed description was provided for a cohort of children with molluscum contagiosum (7).

The point estimate of the centre of the CDLQI score distribution is important as it provides detail of the average severity and potential cost of a condition. However it does not convey the distribution of scores or allow one to determine how many children may need to be treated in specialist centres or receive more active/complex therapies. These therapies can be costly and of great significance to both primary and secondary care due to them requiring more frequent consultations and potentially more expensive management.

A comprehensive review (3) of all publications reporting use of the CDLQI has revealed strengths and weaknesses concerning its validation. There is evidence of high internal consistency, test–retest reliability, responsiveness to change, and significant correlation with other subjective and objective measures. However Rasch analysis has not been carried out and more information is needed concerning minimal clinically important difference; these are areas requiring further study. One study (13) identified that Factor loading scores of a two-factor solution of CDLQI items ranged between 0\_07–0\_74 for factor 1 and 0\_09–0\_83 for factor 2: further work is needed to assess the question of unidimensionality of this instrument.

The main limitations of this meta-analysis are that data from studies using various designs and different populations have been combined and the data may not be generalisable to other settings. Typically dermatologists are referred the most severe and complicated cases from primary care, and so the CDLQI scores reported from secondary care may be higher than typical cases existing in the community; however in conditions in which data is available from both secondary care and

community settings for adults using the DLQI, the QoL scores were comparable (18). There is also the possibility that a greater impact upon QoL may be a determinant of referral to secondary care, along with the severity of disease, parental QoL, and impact upon daily activities, all of which may interact with the child's QoL. The CDLQI has not been formally validated as a QoL measurement questionnaire in the primary care or community setting, however where the Dermatology Life Quality Index (DLQI) was used to assess the impact of skin conditions on QoL in adults, the scores in primary care were comparable to that of patients seen in secondary care(18). The spectrum of QoL impact of skin disease experienced by children seen by dermatologists may differ depending on whether patients are seen directly by dermatologists or whether they are initially seen by primary care "gatekeepers". A high CDLQI score may be helpful information to primary care physicians, prompting appropriate urgent referral to secondary care or informing management decisions.

A limitation of this systematic review is that only one author reviewed the papers and conducted data extraction for the search. It is however best practice for both the systematic search results and data extraction to be reviewed independently by at least two reviewers to minimize the chance of missing relevant information. The search could have been influenced by the bias inherent in having only one reviewer, and this may reduce the validity of our results. To provide transparency in the search methods, and conforming to the PRISMA statement (19), the method of study selection including search strategy, process for selecting studies, and method of data extraction have been described explicitly in the Methods section above and consistently adhered to.

There are many methods to measure the impact of a skin condition on QoL: the CDLQI is an instrument which can be used across many different skin conditions in affected children. In general, generic instruments are not as sensitive, responsive or relevant to individual patients as disease specific instruments(20). However for most skin conditions in children no disease specific measures exist, and from the practical clinical perspective it is easier for clinicians to use and become familiar with the meaning of scores of a single dermatology-specific instrument. The CDLQI has been used in over 100 published studies, providing a rich and wide data source allowing comparison of QoL impact for a combined sample of 7,798 children with 20 skin conditions to be presented within one meta-analysis.

We excluded studies based upon language (search limited to English language only). This aspect of the search strategy is a limitation of the study as potentially important findings may have been excluded. However excluding research published in languages other than English has been found to have little effect on summary effect estimates(21).

The CDLQI is a useful instrument which can measure the impact of skin disease on QoL in populations of children whether or not other non-skin conditions are present, and allows comparisons between children with a wide range of different skin conditions(2). The results of this study provide overall CDLQI scores for individual conditions that may assist treatment planning and the interpretation of scores in the clinical setting and in future studies.

**What's already known about this topic?**

- Skin conditions can impact upon a child's quality of life.
- Quality of life measures that inform treatment planning are more likely to be used in clinical practice.

### What does this study add?

- Overall, childhood skin conditions have a mean “small” effect on quality of life but there is a wide range of severity experienced by individual children.
- Most skin diseases are associated with a major impact on dermatology specific life quality in a small proportion of children.
- This review provides a guide for clinicians in interpreting the quality of life impact of a skin condition and may inform treatment planning.

### Conflicts of interest

A.Y.F. is joint copyright owner of the CDLQI and the DLQI. The other authors declare no conflicts. Cardiff University gains some income from the use of these measures.

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### Role of the funding body

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

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## Tables

**Table 1: Conditions describing proportion of children and severity of QoL impact**

Condition	QoL impact severity bandings (4)		
	None or small	Moderate	Large or extremely large
Acne (22)	67.0%	28.0%	5.0%
Acne (23)	90.0%	8.1%	1.6%
Atopic eczema (16)	28.0%	38.0%	34.0%
Erythropoietic protoporphyria (24)	20.0%	80.0%	
Molluscum contagiosum (7)	71.8%	17.3%	10.9%
Vitiligo (25)	88.0%	5.0%	7.0%

## Figure Legends

Figure 1: Flow chart of study selection process

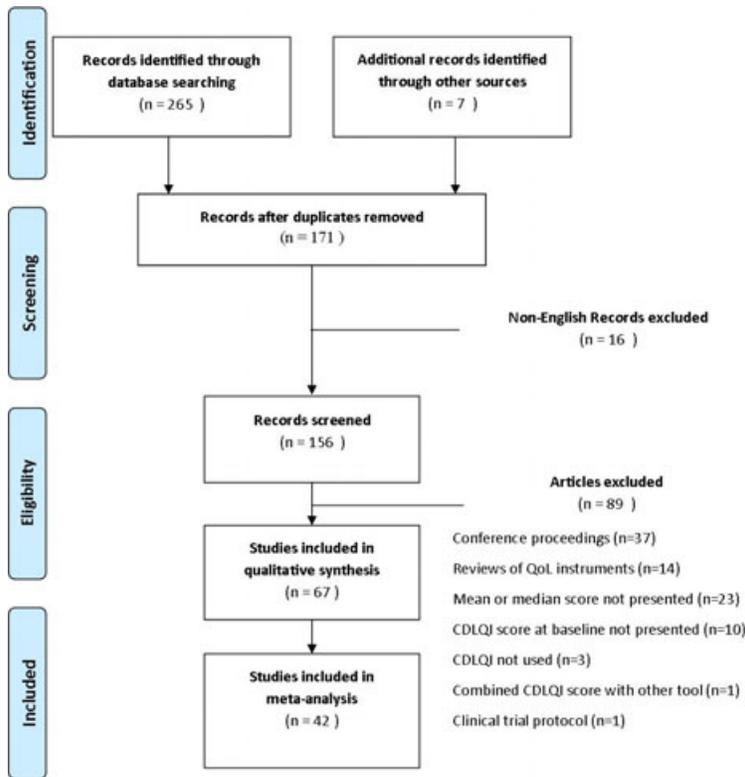


Figure 2: Comparison of mean CDLQI scores by skin condition

Note: CDLQI scores reported in 67 studies. Each horizontal line represents the range of scores with the mean indicated. The solid vertical line represents the overall mean. The dotted vertical lines divide the score band descriptors(4): 0-1 = no effect on QoL, 2-6 small effect, 7-12 moderate effect, 13-18 very large effect, 19-30 extremely large effect.

