

SHORT REPORT

Comparison of the impairment of family quality of life assessed by disease-specific and dermatology-specific instruments in children with atopic dermatitis

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Abstract

Background Quality of life (QoL) of family members of patients with chronic skin diseases is often impaired. Disease-specific family QoL instruments for most of the skin conditions are not available. Family Dermatology Life Quality Index (FDLQI) is a dermatology-specific family QoL instrument that has been used in few studies to assess the impact of skin diseases on family members of mixed adult and children patient population. However, its use in families of exclusively paediatric patients with skin conditions needs further investigation.

Objectives The aim of this study was to compare the results of two family QoL instruments; the disease-specific Dermatitis Family Impact (DFI) questionnaire and the dermatology-specific FDLQI.

Method The original UK English version of the FDLQI was translated into Ukrainian using the standard translation guidelines. Parents of 30 children with AD were asked to complete the Ukrainian versions of the FDLQI and the DFI questionnaires. Disease severity was estimated using the Scoring Atopic Dermatitis (SCORAD).

Results Mean FDLQI score was 11.8 (± 5.8 ; range = 0–30) and the mean DFI score was 10.7 (± 5.6 ; range = 0–30). Mean SCORAD was 40.6 (± 11.3 ; range = 0–103). Both questionnaires showed good internal consistency with a Cronbach's alpha value of 0.83 for both. The FDLQI showed high correlation with the DFI ($r = 0.68$, $P < 0.0001$). Items of each questionnaire having similar themes also demonstrated high correlation.

Conclusion Family Dermatology Life Quality Index may be effectively used by parents of children as it can be used by family members of adult dermatology patients. Although, in some clinical and research situations, disease-specific measures could be replaced by the dermatology-specific measures, in most situations combining the disease-specific and dermatology-specific measures would be the most suitable approach to gain comprehensive insight into the impact of a dermatological condition on family members.

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Conflicts of interest

MKA Basra is a joint copyright owner of the FDLQI.

Funding sources

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Introduction

The interest in the assessment of quality of life (QoL) of children with dermatological conditions is growing. Several national guidelines for management of skin conditions in children recommend health-related QoL (HRQoL) measurement as part of the assessment process. Moreover, QoL assessment plays an important role in educational programmes for children with chronic skin conditions and their parents.¹ Of all skin diseases affecting children, atopic dermatitis (AD) is most well known for its substantial impact on the child's QoL.² What is less well

known is the wider effect of this condition on the QoL of child's parents and other family members. A disease-specific instrument, the Dermatitis Family Impact (DFI) questionnaire was created in 1998 to assess the impact that AD has on parents' QoL.³ However, until now there are no disease-specific instruments to assess family QoL in most of the other skin conditions. More recently a dermatology-specific measure called the Family Dermatology Life Quality Index (FDLQI)⁴ has been developed that can be used for any dermatological condition. Both these questionnaires consist of 10 questions with each question scored

on a 0–3 scale and maximum scale score of 30. The higher the score the greater the impact on family's QoL. The time frame for DFI questionnaire is 1 week, whereas it is 1 month for the FDLQI. The DFI has been developed specifically for the parents of children with AD, whereas the FDLQI assesses the family impact across different skin diseases irrespective of the age of patients.

The aim of this study was to compare the results of two different family QoL instruments; the disease-specific DFI questionnaire and the dermatology-specific FDLQI.

Materials and methods

The original UK English version of the FDLQI was translated into Ukrainian by two independent translators and then back-translated into English by two other independent translators. Final back translation was confirmed by one of the FDLQI authors (MKAB). The probe technique for pre-testing was used. Information on creation and validation of the Ukrainian version of the DFI questionnaire has previously been published.⁵

Parents of 30 children (under the age of 4 years) with AD (15 boys and 15 girls) attending the outpatient's dermatology clinic were asked to complete the Ukrainian versions of the FDLQI and the DFI questionnaires. Mean age of children in months was 31.7 (± 18.3). The diagnosis of AD was made using the criteria of Hanifin and Rajka.⁶ Disease severity was estimated by the same dermatologist using the Scoring Atopic Dermatitis (SCORAD) – a clinical disease severity instrument that combines information on the involved area of skin, as well as objective and subjective symptoms in patients with AD.⁷ In all cases, mothers completed the questionnaires. It has been shown previously that the gender of parent who filled in the DFI did not significantly influence the results.⁸ Ethical permission for the study was granted by the research ethics committee of the National Medical Academy for Postgraduate Education. All study subjects (i.e. parents) signed the informed consent forms.

Statistical methods

Data are presented as mean and standard deviation of the mean. Unpaired *t*-test with Welch correction (two-tailed *P* value) and non-parametric correlation (Spearman's rho) were used. The results were considered significant if *P* < 0.05. Cronbach's alpha was used to measure internal consistency of the Ukrainian versions of the FDLQI and the DFI.

Results

All 30 mothers of children with AD filled in the questionnaires without any difficulty (Figs 1,2). The mean FDLQI score was 11.8 (± 5.8 ; range = 0–30) and the mean DFI score was 10.7 (± 5.6 ; range = 0–30). The highest scoring items of the FDLQI were questions on emotional distress (2.27 ± 0.91), time spent on looking after relative/partner (1.63 ± 0.76) and increased household expenditure (1.60 ± 0.86). The highest scoring DFI

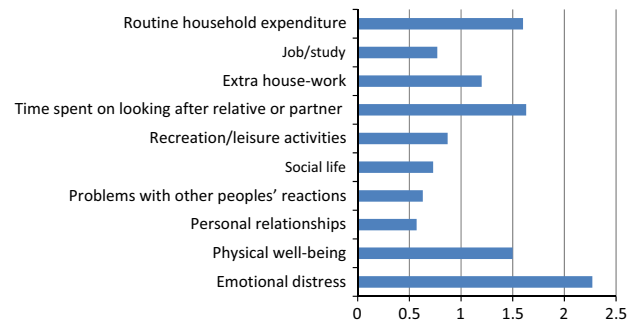


Figure 1 FDLQI items results.

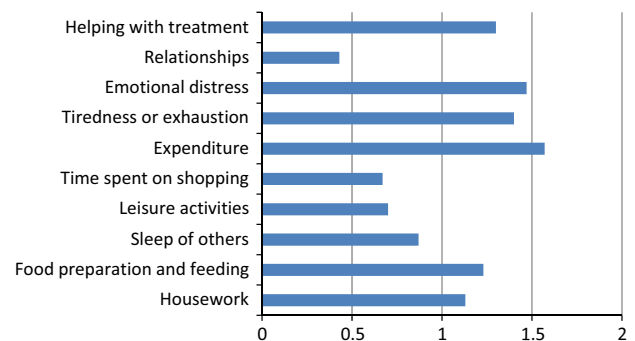


Figure 2 DFI items results.

items were questions on family expenditure (1.57 ± 0.63), distress (1.57 ± 0.63) and tiredness (1.40 ± 0.16). Mean SCORAD was 40.64 (± 11.30 ; range = 0–103). Both questionnaires showed good internal consistency with a Cronbach's alpha value of 0.83 for each measure. The FDLQI correlated very well with the DFI ($r = 0.68$, $P < 0.0001$). Correlations between the FDLQI and the DFI items that represented similar themes were also significant as shown in Table 1. However, neither of the two questionnaires showed significant correlation with SCORAD ($r = -0.13$, $P = 0.049$ for the FDLQI and $r = -0.22$, $P = 0.26$ for the DFI).

Mean age, SCORAD, FDLQI and DFI questionnaire scores did not differ significantly between boys and girls (Table 2).

Discussion

Most of the published studies on the FDLQI measured family QoL of adult patients with skin diseases.^{9,10} However, one of the key publications on the FDLQI¹¹ reported use of this questionnaire in family members of patients with age range from 5 months to 84 years. In a study by Katugampola *et al.*¹² family QoL of 12 family members of 20 patients with congenital erythropoietic porphyria was assessed by means of the FDLQI. Eight of these patients were children with age ranging from 7.6 to 14.8 years. The mean FDLQI score of parents or spouses of 12 adult patients was 8.7 and the mean FDLQI score of parents of

Table 1 Correlations between the FDLQI and the DFI items representing similar themes

FDLQI item	DFI item	Correlation (r)
Emotional distress	Emotional distress	$r = 0.44, P = 0.02$
Physical well-being	Tiredness or exhaustion	$r = 0.71, P < 0.001$
Physical well-being	Sleep of others	$r = 0.46, P = 0.01$
Personal relationships	Relationships between the main carer and partner or between the main carer and other children	$r = 0.38, P = 0.04$
Problems with other peoples' reactions	NA	
Social life	NA	
Recreation/leisure activities	Family leisure activities	$r = 0.36, P = 0.05$
Time spent on looking after relative/partner	Helping with treatment	$r = 0.32, P = 0.08$
Extra house-work	Housework	$r = 0.58$ $P = 0.001$
Extra house-work	Food preparation and feeding	$r = 0.35, P = 0.06$
Job/study	NA	
Routine household expenditure	Expenditure	$r = 0.48, P < 0.01$

Table 2 Mean SCORAD, age, FDLQI and DFI of boys and girls with AD

	Boys with AD (n = 15)	Girls with AD (n = 15)	P
SCORAD	42.41 ± 11.68	38.99 ± 11.08	0.43
Age in months	26.40 ± 11.54	35.73 ± 19.72	0.13
FDLQI	12.20 ± 4.36	11.40 ± 7.11	0.71
DFI	12.00 ± 5.37	9.47 ± 5.69	0.22

SCORAD, Scoring Atopic Dermatitis; FDLQI, Family Dermatology Life Quality Index; DFI, Dermatitis Family Impact.

eight children was 7.8. Sampogna *et al.*¹³ also recently reported use of the Italian version of the FDLQI in adults and children with recessive dystrophic epidermolysis bullosa. There were differences in the FDLQI scores between various age groups of patients but not between children and adults. We selected children with AD less than 4 years old for the study because this age group is quite different from adult patients, as they cannot provide self-ratings and are also mostly dependent on the family for their care.

To the best of our knowledge this is the first study dedicated to the validation of the FDLQI exclusively in the parents of children with a skin condition. It has demonstrated an overall significant correlation between the DFI and the FDLQI scores. Interestingly, in each measure, majority of the items that represented similar themes demonstrated significant correlations as will be discussed later. However, three items in the FDLQI (Q4: problem due to people's reaction; Q5: effect on social life; Q9: effect on job or study) and one item in the DFI (Q5: family shopping) did not have any corresponding item in the counterpart measure. Question 1 of the FDLQI and question 8 of the DFI ask about the emotional distress in the family member/parent caused by the skin condition of the patient. The correlation coefficient between these two items

was $r = 0.44$ ($P = 0.02$). The FDLQI item 2 representing impact on physical well-being of the family member was highly correlated with item 7 of the DFI representing tiredness and moderately correlated with item 3 representing sleep. It is worth noting that the element of sleep is also encompassed by the FDLQI item 2 as part of the wider impact on well-being of which sleep and rest are part and parcel. Similarly other items in these measures with almost similar wording showed natural correlation such as items on impact on leisure activities (item 6 of the FDLQI and item 4 of the DFI), family expenditure (item 10 of the FDLQI and item 6 of the DFI), relationships (item 3 of the FDLQI and item 9 of the DFI) and increase in the house work (item 8 of the FDLQI and item 1 of the DFI). Item 7 of the FDLQI representing burden of care in terms of time spent on treatment and item 10 of the DFI asking the effect of helping with treatment did not show significant correlation possibly due to slight difference in the context of the questions. The item in the FDLQI specifically asks for the amount of time spent by the carer/family member on treatment of the patient whereas the focus of the corresponding item in the DFI is on the effect of helping with the treatment on carer's life which has a much broader meaning and is not as specific as the wording of the item in the FDLQI.

Correlation between the FDLQI or the DFI with SCORAD in our cohort was not statistically significant. Monti *et al.*¹⁴ previously found moderate correlation of the DFI with objective SCORAD. Meanwhile, in a study by Ganemo *et al.*¹⁵ such correlation was not statistically significant. These data represent an inconsistent trend in association between subjective QoL and relatively more objective physical disease severity assessments.

There was no gender difference with regard to the FDLQI and the DFI results between boys and girls in our study. It has been previously shown that such gender differences should be

adequately studied only on scrupulously matched subjects when each child in the group of boys is matched to a corresponding child in the group of girls whose age in months and SCORAD value are almost identical.¹⁶

Use of these measures in a single centre with a particular language version could be thought to restrict the generalizability of the findings of this study. However, recent international multicenter study¹⁷ reported that parents of AD children from different countries assess the DFI in a quite similar manner. In conclusion we can see that out of 10 items in each of these two questionnaires, at least 6 had significant correlation with corresponding items in their counterpart measure. This implies that in some research as well as clinical situations, disease-specific measures could be replaced by the dermatology-specific measures without losing much information but with the added advantage of reducing the burden on the respondent. However, we do acknowledge that in most situations combining the disease-specific and dermatology-specific measures would be the most suitable approach to gain comprehensive insight into the impact of a dermatological condition on the family member or the carer. Our results also showed that the FDLQI may be effectively used in parents of children as in adult population. Further larger and multicentre studies would be required to confirm these preliminary findings.

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