

Childhood Atopic Dermatitis: A Measurement of Quality of Life and Family Impact

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Summary

Atopic dermatitis is the commonest skin disease in children, causing psychological, social and functional disability to them and their families. This study assessed the family impact and quality of life using the translated Malay version of The Dermatology Family Impact (DFI)¹ and The Children's Dermatology Life Quality Index (CDLQI)² questionnaires.

Seventy-two children, aged between 6 months and 16 years attending the Paediatric Dermatology Clinic at the Paediatric Institute and the Dermatology Department, Hospital Kuala Lumpur participated in this study. Thirty-nine patients (54.2%) were males and 33 patients (45.8%) were females. The median age of the patients was 74 months (Q1 6, Q3 104 months). The median age of diagnosis was 22 months (Q1 1, Q3 36 months). The median disease duration was 44 months (Q1 3, Q3 65).

The severity of eczema was assessed using the SCORAD severity index (maximum score = 83). The median SCORAD (European Task Force On Atopic Dermatitis) score was 36 (n=72, SD=16.2). The majority of patients in this study suffered from moderately severe eczema (n= 40, mean, SCORAD=29.3) followed by severe eczema (n= 27, mean SCORAD= 54.3). The mildly affected patients formed the minority group (n= 5, mean SCORAD=9.0).

The family impact was shown to be greater in severe atopic dermatitis compared to moderate atopic dermatitis (Anova, p=0.02). The children's quality of life impairment was also greater in severe atopic dermatitis compared to moderate atopic dermatitis (Anova p=0.08). This study confirms that quality of life and family impact are related to the severity of atopic dermatitis.

Key Words: Atopic dermatitis, Scoring System of Atopic Dermatitis (SCORAD), Family impact, Quality of life

Introduction

Atopic dermatitis is a chronic disease that improves and remits with time. It may affect

parental life style and parent-child relationship. The effect can be enormous and attempts must be made to improve this situation. Atopic dermatitis

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may have profound effects on the quality of life, social relationships and development. It also interferes with school and physical activities. Sufferers of atopic dermatitis may be subjected to teasing from colleagues and became self-conscious. Treatment may be demanding with frequent hospital attendances^{3,4}. Psychologically, individuals suffering from atopic dermatitis either children or adults have been shown to suffer a higher level of anxiety and lower quality of life^{5,6}. Quality of life is a reflection of the way that patients perceive and react to their health status and other non-medical aspects of their lives⁷. These perceptions are best determined as an overall quality of life, which includes physical, functional, emotional and mental well being, but also non-health-related elements such as family, friends and other life circumstances. The objectives of this study were i) to determine the reliability of the translated version of the DFI and CDLQI questionnaires in Bahasa Malaysia and ii) to measure the family impact and quality of life in children with atopic dermatitis in a local hospital based population.

Materials and Methods

This was a cross-sectional study conducted at the Paediatric Dermatology clinic of Institut Pediatrik and the Dermatology Department, Hospital Kuala Lumpur. This study involved a sample size of 70 patients for Dermatology Family Impact (DFI) and 33 patients for Children Dermatology Life Quality Index (CDLQI) questionnaires. During one month period from March 21st to 28th April 2000, all children aged 0 to 16 years with a diagnosis of atopic dermatitis fulfilling Hanifin and Rajka criteria⁸, attending the Paediatric Dermatology Clinic in Institut Paediatric and Dermatology Department, Hospital Kuala Lumpur were invited to participate in this study. Verbal consents were obtained from all participating parents. The exclusion criteria were patients or siblings suffering from any significant medical condition

such as epilepsy, mental retardation, post-liver transplant, alopecia universalis and cerebral palsy. There was also a minority of patients whose parents did not consent due to the short interval for review.

The DFI and the CDLQI questionnaires, which were specifically designed to measure the quality of life of children with atopic dermatitis and the family impact of childhood atopic dermatitis, were used in this study. Both the questionnaires were chosen because of their simplicity, good content and face validity. These questionnaires were similar to the adult questionnaire (Dermatology Life Quality Index), which was more established and used in various studies⁹. The CDLQI questionnaire has been validated and has been used in several studies. Written permission to use both questionnaires was obtained from the author, Professor A.Y. Finlay of University of Wales College of Medicine, Cardiff, U.K.

The questionnaires were translated into Bahasa Malaysia and then conferred on a single version. Another two separate translators retranslated the single Malay version into English. The back translation was then examined to check that they were the exact equivalent to the original English version. The validity of both questionnaires was tested using Kappa analysis of agreement within two weeks intervals. The analysis was performed for each individual questions to determine the degree of agreement. A Kappa agreement greater than 0.75 indicates excellent agreement, values between 0.4 to 0.75 indicates fair to good agreement and values below 0.4 indicates poor agreement.

Both questionnaires were self-administered. The DFI questionnaire was given to all parents in the study population and the CDLQI questionnaire was given to patients aged seven years to 16 years. The questionnaires were tested on two separate occasions, within two weeks interval to

check the reliability and repeatability. Patients who failed to return for the second interview were interviewed via the telephone.

The atopic dermatitis severity scoring for all patients were performed by the primary investigator during both visits. Patients continued on oral antihistamine as part of their treatment. There were no changes made in the steroid potency during this study period. Patients who suffered from intercurrent skin infection were treated with oral antibiotics.

Statistical Analysis

Statistical analyses were performed using SPSS 10.0.1 for Windows 98. Internal consistency reliability of both the translated versions of the DFI and CDLQI questionnaires was determined using Cronbach's alpha coefficient. Further analysis of each questions in both questionnaires were evaluated using the Spearman rho correlation co-efficient. Agreement of the questionnaires was measured using Cohen's Kappa. Paired t-test and ANOVA were used in measuring statistical significance for parametric data.

Results

Population Sample

Eighty-five patients aged between six months to fifteen years initially consented to participate in the study. Six were excluded due to co-existing significant medical illness i.e. post-liver transplant, alopecia totalis, epilepsy, and mental retardation. One patient was excluded because of the presence of a sibling with cerebral palsy. Seventy-two patients completed the second interview. However only 59 patients returned for review after two weeks and the remaining 14 patients were interviewed via telephone. Seventy parents participated in the DFI questionnaire and 33 patients aged seven years and above participated in the CDLQI questionnaire. The results are summarised in Table I.

As a tertiary centre, the majority of the patients were suffering from moderate and severe atopic dermatitis. Patients with mild atopic dermatitis were usually followed up in the general paediatric clinic or at the primary care centre.

The mean SCORAD score on the first visit was 38.9 (SD 15.5) and the following visit mean score was 34.6 (SD 16.4). The difference of the SCORAD scores after two weeks interval was 4.3 (SD 10.6, paired t- test, $p=0.003$)

Four of the patients were admitted during the study period. One patient was admitted for severe skin infection and another three patients were admitted for wet wrap administration.

Reliability and Repeatability of DFI and CDLQI Questionnaires

The Cronbach alpha score for the DFI questionnaire was 0.85 (10 items tested, $n=70$) and the CDLQI questionnaire was 0.92 (10 items tested, $n=33$). The Spearman's correlation for both questionnaires showed a good correlation between the mean total score during the first and second interview. The DFI Spearman correlation co-efficient was 0.7 ($p<0.01$) and the CDLQI correlation coefficient was 0.74 ($p<0.001$)

The validity of both questionnaires was tested using Kappa analysis of agreement within two weeks intervals. The Kappa analysis from both questionnaires showed an average of moderate agreement between the two interviews within two weeks intervals. The question that scored the highest Kappa in the DFI questionnaire dealt with family diet. The children's impact scored highest Kappa agreement with regards to emotional and school disturbance and clothing.

Dermatitis Family Impact Questionnaires

Forty-four respondents were mothers, fifteen were fathers and three were guardians. Eight others were inconsistent respondents in which the initial respondent were not available during

the second interview. These subjects were not excluded since the measurement was about the family impact and quality of life. Two parents had two children suffering from atopic dermatitis and only responded once.

The majority of the parents had completed secondary education (n= 94). Forty-two parents had completed tertiary education and eight parents had completed primary education. Forty-two mothers were housewives while 30 were working.

The DFI questionnaire mean score was 9.4 (SD 5.3) during the first interview and 7.8 (SD 4.8) during the second interview (maximum score=30). In comparison, unaffected families scored only 0.4 (SD 0.9) in the original study.¹

The parental score of DFI was 5.2 (SD 4.4, n=5) in mild atopic dermatitis, 8.5 (SD 5.1, n=38) in moderate atopic dermatitis and 11.5 (SD 5.2, n=27) in severe atopic dermatitis. There was a significant difference of the DFI scores between the moderate and severe atopic dermatitis (ANOVA, p= 0.02, 95% CI 0.4, 5.5). It is interesting to note that the highest scores were in questions concerning family diet (1.0, SD 0.8), sleep loss (1.23, SD 0.9), the parents' emotional disturbance (1.1, SD 0.9), exhaustion (1.1, SD

0.9) and treatment (1.0, SD 0.9), which were above the arbitrary cut-off point of 1.0. Figure 1 shows the mean scores of DFI individual questions

The Children's Dermatology Life Quality Index Score

The children's impact questionnaire mean score was 10.0 (SD 6.6) during the first interview and 7.6 (SD 6.2) during the second interview (maximum score=30). In comparison, normal controls scored only 0.4 (SD 0.7) in the original study².

The children scored 6.5 (SD 7.8, n=2) in mild atopic dermatitis, 8.8 (SD 5.9, n=21) in moderate atopic dermatitis and 13.2 (SD 7.1, n=10) in severe atopic dermatitis. There was almost a significant difference of the CDLQI scores between the moderate and severe atopic dermatitis (ANOVA, p=0.08, 95% CI 0.6, 9.4).

In contrast to their parents, the CDLQI scored highest in other aspects. The domains were concerning their symptoms e.g. itchiness and soreness (1.8, SD 0.7), emotional disturbance (1.2, SD 1.0), leisure activities (1.0, SD 0.9), school disturbance (1.1, SD 0.9) and sleep loss (1.2, SD 0.8). Figure 2 shows the mean scores of CDLQI individual questions.

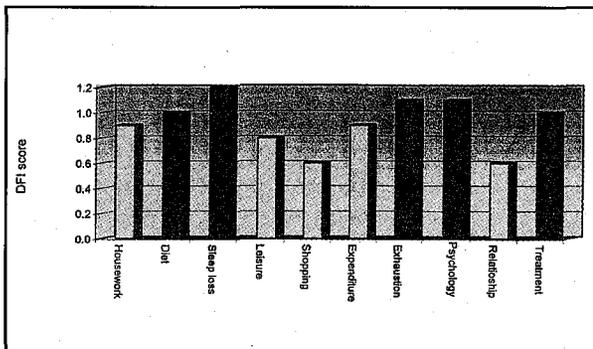


Fig 1: Mean score of DFI individual questions

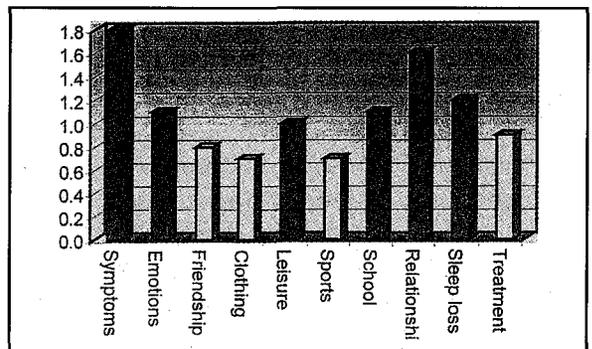


Fig 2: Mean scores of CDLQI individual questions

Table 1: Characteristics of patients participating in the study

1. Sex	Male	39 (54%)
	Female	33 (46%)
2. Race	Malays	150 (69%)
	Chinese	10 (14%)
	Indians	10 (14%)
	Punjabi	2 (3%)
3. Age (Median)	74 months	Q1 40, Q3 104
4. Age at Diagnosis (Median)	22 months	Q1 6, Q3 36
5. Disease Duration (Median)	44 months	Q1 24, Q3 65
6. Scord Severity Score (Mean)		
1st visit (n=72)	37.9	SD 37.9
2nd Visit (n=59)	4.6	SD 16.4
7. Scord score according to severity of atopic dermatitis (Mean)		
Mild (n=5)	9.0	SD 3.5
Moderate (n=40)	29.3	SD 7.8
Severe (n=27)	54.3	SD 8.2
8. Sleep score (Mean)		
1st visit	5.44	SD 2.0
2nd visit	3.86	SD 2.8
9. Number of previous hospital admissions due to atopic dermatitis		
Once	7 (10%)	
Twice	2 (3%)	
Four	2 (3%)	

Discussion

Atopic dermatitis is the commonest skin disease of childhood and constitutes 40% of referrals to the Paediatric Dermatology clinic. Being a tertiary center, the majority of our patients had moderate and severe atopic dermatitis. The mildly affected atopic dermatitis patients are usually treated in the primary care centres, outpatient clinics and the general paediatric clinics, especially the asthma clinic. Hence these group of patients were captured for comparisons.

The patient sample was hospital based and thus the demography does not reflect the prevalence

of the local urban population in Kuala Lumpur. Another local community survey in Kuala Lumpur reported a prevalence of atopic dermatitis at about 6.5%¹⁰. There was marked ethnic disparity in the referrals of atopic dermatitis patients, which reflected the pattern of public hospital utilization and did not reflect the true prevalence of atopic dermatitis in the various ethnic groups in Malaysia. The cross-sectional prevalence rates of other associated atopic diseases such as asthma (36%) and allergic rhinitis (56%) in this study were in keeping with other reports by various authors¹⁰. Burks quoted from a cohort on atopic dermatitis patients, that 50% of them eventually develop

asthma and 80% develop asthma or allergic rhinitis¹².

There was marked improvement in the severity score after two weeks. The explanation might be that the interval of two weeks was adequate to expect improvement in atopic dermatitis. There was also a small number of patients who had mild exacerbation during the first interview due to mild skin infection and not requiring admission. This minority group was treated with a short course of antibiotics and improved after two weeks. Another three patients who had severe symptoms were administered wet wrap during the study. This group of patients also had a marked improvement in their symptoms after two weeks.

An alteration to the question concerning family leisure activities had to be made to the DFI questionnaire to adjust to the local population. For example, leisure activities in the local context usually involve outings, which replaced swimming, as in the original questionnaire. The original author used the questionnaire in children between three to 16 years. However, in our local context, it was not practical to administer the questionnaire to children under seven years or pre-school going age as the results may be frustrating in terms of the quality of responses. Both of these questionnaires were self-administered most of the times. However, there was a minority of parents who were illiterate and had to be interviewed by the investigator as a single constant interviewer (n=5).

The Cronbach alpha analysis showed a very good result for both questionnaires indicating that the translated versions had a very good internal reliability and all the questions correlated highly with each other, as in the original English questionnaire.

The impact of atopic dermatitis on the family has been well established. This study has demonstrated that atopic dermatitis has a profound impact on personal, social, emotional

and financial perspectives of families. Su J.C. et al have demonstrated similar findings and found that the impact of moderate and severe atopic dermatitis was even greater than insulin dependent diabetes mellitus^{13,14,15}.

Dietary restriction has a significant impact on the family diet, especially on those with moderate and severe atopic dermatitis. Only three patients in this study who had severe atopic dermatitis or history suggestive of angioedema had been tested for specific Ig-E and shown to have multiple food allergies¹¹. In the other patients inferences were based on parental observations. However, the majority of parents strongly believed that food restriction should be practised, mostly due to local traditional belief.

This study has shown that severe atopic dermatitis affected sleep more. Disturbed sleep is a significant factor, which contribute to both child and parental morbidity¹³. An Australian study has quoted an average of 1.9 hours per night sleep loss by parents of severely affected atopic dermatitis¹⁴. In comparison, an English study has demonstrated 2.6 hours per night parental sleep loss¹⁵. These findings had serious consequences leading to reduce parental employment for 40% of parents looking after the moderate and severe atopic dermatitis in the Australian study¹⁴.

Caring for a child with atopic dermatitis is a demanding job for anyone, but for the mothers it is an exhausting one¹⁶. Sleep problems were the major contribution to the distress of the disease. Difficulties were exerted both during day and night, especially when the child's symptoms worsened. The despair of mothers was doubled with extra work of the disease on minimal amount of sleep¹⁶.

Atopic dermatitis generates an extra burden of mothering such as the time consumed in treatment application, bathing and extra burden of housework such as washing, dusting and

cleaning in order to avoid potential allergen. Atopic dermatitis also requires modification to the family lifestyle including social and leisure activities. It was noted that heat avoidance was a major concern in this study. Parental perception to treatment was shown to be greatly affected by their child's disease severity and consequently treatment compliance. The severe atopic dermatitis has scored significantly higher than the milder group in terms of parental perception to treatment¹⁷.

Children with moderate and severe atopic dermatitis suffered from lack of confidence, self-consciousness and irritability, demonstrated by two patients in this study who were referred to the psychiatrist for counselling. Absolon et al. have found that children with moderate to severe atopic dermatitis are at high risk of developing psychological difficulties, which may have implications for their academic and social development^{18,19,20}.

Sleep loss was also demonstrated to have high impact in the children's quality of life²¹. The patients' score was almost equally high in the mild group. There was also persistence of sleep

disturbance in majority of patients despite remission and improvement in severity score. This could be explained by Reuveni's evidence from his study that sleep disturbance in atopic dermatitis patients in clinical remission was not related to scratching per se, but also awakenings and arousals due to itchiness but not severe enough to cause scratching^{22,23}.

This study has demonstrated that the children's high impact life quality index is related to symptoms, emotional disturbance, leisure activities, school disturbance and sleep loss. These results were similar to the multicentre audit by the British Association of Dermatologists²⁴.

This study has shown that patients and families with moderate and severe atopic dermatitis suffer greater impact in the quality of life than those with mild atopic dermatitis. The high impact domains of the family quality of life in atopic dermatitis were family diet, parental sleep loss, psychological pressure and exhaustion. The children's impact was higher in issues surrounding their symptoms, emotional disturbance, leisure activities, sleep loss and school disturbance.

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Appendix 1

THE FAMILY IMPACT ECZEMA QUESTIONNAIRE

Score

The aim of this questionnaire is to measure how much your child's skin problem has affected you and your family over the last week. Please tick one box for each question.

- | | |
|---|---|
| 1. Over the last week, how much effect has your child having eczema had on your housework, eg washing, cleaning. | very much
quite a lot
a little
none at all |
| 2. Over the last week, how much effect has your child having eczema had on preparation and feeding. | very much
quite a lot
a little
none at all |
| 3. Over the last week, how much effect has your child having eczema had on the sleep of others in the family. | very much
quite a lot
a little
none at all |
| 4. Over the last week, how much effect has your child having eczema had on family leisure activities, eg swimming. | very much
quite a lot
a little
none at all |
| 5. Over the last week, how much effect has your child having eczema had on time spent on shopping for the family. | very much
quite a lot
a little
none at all |
| 6. Over the last week, how much effect has your child having eczema had on your expenditure, eg costs related to treatment clothes etc | very much
quite a lot
a little
none at all |
| 7. Over the last week, how much effect has your child having eczema had on causing tiredness or exhaustion in your child's parents/carer. | very much
quite a lot
a little
none at all |
| 8. Over the last week, how much effect has your child having eczema had on causing emotional distress such as depression, frustration or guilt in your child's parents/carer. | very much
quite a lot
a little
none at all |

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- | | |
|---|---|
| 9. Over the last week, how much effect has your child having eczema had on relationships between the main carer and partner or between the main carer and other children in the family. | very much
quite a lot
a little
none at all |
| 10. Over the last week, how much effect has helping with your child's treatment had on the main carer's life. | very much
quite a lot
a little
none at all |

Please check that you have answered every question. Thank you.

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Appendix 2

CHILDRENS DERMATOLOGY LIFE QUALITY INDEX QUESTIONNAIRE

Score

The aim of this questionnaire is to measure how much your skin problem has affected you over the last week. Please tick one box for each question.

- | | |
|---|---|
| 1. Over the last week, how itchy, scratchy, sore or painful has your skin been? | very much
quite a lot
a little
none at all |
| 2. Over the last week, how embarrassed or self conscious, upset or sad have you been because of your skin? | very much
quite a lot
a little
none at all |
| 3. Over the last week, how much has your skin affected your friendships? | very much
quite a lot
a little
none at all |
| 4. Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin? | very much
quite a lot
a little
none at all |
| 5. Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies? | very much
quite a lot
a little
none at all |

Childhood Atopic Dermatitis: A Measurement of Quality of Life and Family Impact

6. Over the last week, how much have you avoided swimming or other sports because of your skin trouble?
- very much
quite a lot
a little
none at all
7. Last week, was it school or holiday time?
If school time: over the last week, how much did your skin affect your school work?
OR
If holiday time: how much over the last week, has your skin Problem interfered with your enjoyment of the holiday?
- very much
quite a lot
a little
none at all
8. Over the last week, how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?
- very much
quite a lot
a little
none at all
9. Over the last week, how much has your sleep been affected by your skin problem?
- very much
quite a lot
a little
none at all
10. Over the last week, how much of a problem has the treatment for your skin been?
- very much
quite a lot
a little
none at all

Please check that you have answered every question. Thank you.

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