

## **The Impact of Libyan Pediatric Atopic Dermatitis on their Families**

### **Abstract**

#### **Background:**

Atopic dermatitis (AD) and psoriasis are common chronic skin diseases affecting children. These disorders negatively impact the quality of life (QoL) of patients in health related aspects such as physical, psychosocial, and mental functioning. This health impact is more accurately represented when accounting for the numerous co-morbidities associated with each disorder.

#### **Aim of the study**

To assess the impact of atopic dermatitis on families of children under four years with the condition and to identify factors affecting family impact, in addition to correlate the impact with their quality of life.

#### **Materials and method:**

A cross sectional survey conducted over period of 6 months. The study include 100 families of children aged 4 years and below, with the diagnosis of atopic dermatitis attending outpatients dermatology clinic at Benghazi medical center and AL-Kish polyclinic, Benghazi-Libya.

Demographic and clinical data were collected directly using interview data collection form.

Three Item Severity (TIS) score included in the study and based on oedema/ papulation, excoriation and erythema. The total score ranged from 0 to 9. To assess the impact of the children's AD on the parents' QoL, the Dermatitis Family Impact Questionnaire was used with score ranges from 0-30, higher score indicated bad quality of life. Data obtained were analyzed using SPSS version 26 at statistical significance 0.05.

#### **Results:**

In this study 100 families of AD children, 50% males, age ranges from 4 to 47 months, 67% had family history of atopy, 47% suffered from other types of atopies. The mean severity index was 4.58. The FDQLI score was ranged from 0 to 26 (mean 16.64) reflecting moderate family impact. AD impact varies among families, to be moderate in 53%, severe in 31, small in 11% and normal in 5%. Ten areas where AD impact the families quality of life were evaluated. Extra expenditure, people reactions, burden of care, people reaction and emotional impact were the most factors showing the greatest impact caused by the presence of AD child in the family. A correlation between FDLQI and disease severity showed that quality of life was significantly more disturbed with increasing severity of the disease. There were no significant differences in families quality of life score regarding the gender and the age of the child, The quality of life showed a significant association with family's educational level. Families with education beyond secondary (fathers and mothers) more severely affected.

#### **Conclusion**

AD appeared to have a moderate impact on the QoL of the enrolled families. QoL measured by FDLQI was significantly more disturbed with increasing severity of the disease. The quality of life showed a significant negative association with family's educational level. To the best of our knowledge this is the first to be reported from Libya and North Africa.

**Keywords:** Atopic dermatitis, children, Family impact, FDQLI, Libya.

## **Introduction**

Atopic dermatitis (AD) is a common inflammatory skin condition that is chronic, recurrent, and extremely itchy, typically starts during childhood and may persist into adulthood (1).

Atopy is described as an inherent propensity to respond to very little amounts of common environmental proteins, such as pollen, house dust mites, and food allergies, by producing increased amount of immunoglobulin E (IgE) antibodies (2).

A wide variety of clinical presentations describe AD, which affects 10- 30% of infants and 2-10% of adults (3). The onset is in infancy in 60% of patients and before 5 years of age in 90%. The disease continues beyond infancy in about one third of infants and affects one third of these children as adolescents (4).

The erythema is ill-defined in the acute stage, and alterations to the skin's surface can include excoriation, exudation, xerosis, crusting, or scaling are the typical symptoms of atopic dermatitis (4,5). Chronic lesions have crusts, scales, lichenification, prurigo, and infiltrating erythema (6). Lichenification is caused by chronic inflammation, often due to repeated scratching and rubbing.

Dry skin may exist in the absence of skin lesions that are still active (5). Pruritus is frequently severe at night but may occur throughout the day (7). More than 50% of patients experienced excessive itch frequency and atopic dermatitis-related sleep problems despite the use of systemic treatments (8). Along with itching and sleep disruption, children with eczema also deal with treatment load, effects on social activities like sports, and shame due to their condition (9).

Psychological health is also impacted by atopic dermatitis. Parents stated that their kids had emotional issues, including sobbing, irritation, behavioral issues, and treatment-related issues (10). Children under four years old who experience parent weariness about worsening of their symptoms and psychological changes. In addition to older children being more self-critical and having lower self-esteem, children between the ages of three and ten may be the targets of bullying, teasing, or exclusion. According to a qualitative study, parents who have children with atopic dermatitis face a greater physical load due to the additional washing, cleaning, and buying needs (11). Parents' sleep was also disturbed by their children, which hampered their ability to socialize. Parents were worn out, apprehensive, guilty, resentful, disappointed, and/or helpless due to the added responsibility. This disease has significant quality of life (QoL), psychosocial functioning and economic consequences, which are not limited to the patient, but extend to the entire family unit (11)..

## **Aims of the study**

1. To assess the impact of atopic dermatitis on families of children under four years with the condition.
2. To identify factors affecting family impact for children under four years with atopic dermatitis.
3. To correlate the impact of under four children atopic dermatitis with their quality of life.

## **Materials and Methods**

Study design:

A cross sectional survey to evaluate the impact of atopic dermatitis in children under four years on their families and assessing the factors affecting their quality of life.

Data collection:

The study include 100 families of children under 4 years with atopic dermatitis, based on clinical manifestation and disease course according to Hanifin and Rajka's diagnostic criteria, attending outpatient clinics of dermatology department, Jumhoria hospital and AL-Kish polyclinic, Benghazi - Libya over 6 months duration. Written consent and right of withdrawal and ensuring confidentiality were issued for every family member attending with the patient.

Exclusion criteria:

Families of complicated cases (e.g. secondary infection), had another co-existing chronic dermatologic condition (e.g. psoriasis, ichthyosis, etc), significant congenital malformation or serious childhood illness.

Data synthesis:

Demographic and clinical data were collected directly using interview data collection form. Three Item Severity (TIS) score; which is a simple clinical tool for assessing severity of AD was included in the formal data collection sheet. It's based on oedema/papulation, excoriation and erythema. The total score will was scale ranges from 0 to 9 and the score was considered mild if it is < 3, moderate 3 – 5 and severe >5.

Family Dermatology Quality Life Index (FDQLI):

To assess the impact of the children's AD on the parents' QoL, Family Dermatology Quality Life Index (FDQLI) questionnaire was used (12,13). The questionnaire includes ten questions about the impact of the children's disease on various aspects of their family members' lives, including emotional distress, physical well-being, relationships, other people's reactions, social life, free time, time spent caring for the child, extra housework, work or education, and daily expenditure. Questions have been raised about the disease's impact on parent's quality of life in the last month. Each question can be answered by selecting one of four answers ranging from 0 to 3. The maximum score is 30 points, and the minimum score is 0 ( Table.1).

## Results

Evaluation socio-demographics:

The age of study subjects varied between 4 and 47 months (mean:24.6 months), the most predominant age group was 13-24 months (31%)( Fig. 1) with equal male to female ratio. Most parents had education levels beyond secondary with 78% for fathers and 52% for mothers( Fig. 2). Fifty three percent of study subjects had only dermatitis whereas 47 % suffered from dermatitis and other types of atopic conditions. Family history of atopic diseases was recorded in 67% of the study subjects. The severity index (TSI) was assessed by mean of total score (1-9), the mean of severity was 4.58. Erythema was absent in 21%, mild in 50% of study subjects, moderate in 29% and severe in 21%, Papulation was absent in 18%, mild in 39%, moderate in 28% and severe in 15%. Excoriation was absent in 39%, mild in 29%, moderate in 15% and severe in 17%. In this study each item of the severity index significantly affect the severity, but excoriation was the most factor that affect the total score.. The mean score of quality of life was (16.46), the maximum was 26, the minimum was 0, which reflect moderate impact on the quality of life. The FDLQI demonstrated 53% of the families had moderate impact on their lives whereas 31 % showed severe impact (Fig. 3). Family Dermatology Life Quality Index score distribution showed different alterations in various functions and activities of the families caused by the disease of their children were recorded. Using the mean score for individual items (range 0–3), the most highly scoring items were monthly expenditures (2.4), people reactions (2.39) and spending time for their children care (2.36) were affected to the highest level, psycho-emotional factor was also implicated (2.29). Other family activities and functions showing various levels of

alterations included daily activities, leisure time, housework, physical wellbeing, relations with other family members and effect on jobs or study (Table 2). The correlation between TSI and FDLQ showed a significant strong positive correlation ( $p < 0.001$ ) is found, where quality of life is severely disturbed by increasing severity of the disease. (Fig.4).

In assessment of severity in correlation to FDLQI according to age, identified that the age group 25-36 months followed by age group  $< 12$  months had moderate correlation and there were no significant differences among different age groups, as shown in table 3. There were significant differences in family quality of life according different education level of both father and mothers, Families with education beyond secondary (fathers and mothers) more severely affected, as represented in tables ( Fig.5).

## Discussion

Atopic dermatitis persists until adulthood in 17-70% of affected patients, and thereby posing a burden on patients and their families (14). AD has significant physical, psychological and financial burdens. Eczema has the most disability adjusted life years of any skin condition included in the Global Burden of Disease Study 2010 (15).

In this study 100 families of AD children were enrolled (50% males, age range 4-47 months, 67% had family history of atopy, 47% suffered from other types of atopies) were evaluated regarding their quality of life using FDLQI and the impact of disease severity. Many studies reported the presence of family history for atopy among the enrolled families, in this study 67% had family history of atopy. Children with one allergic parent becomes allergic 50% of the time, increasing to 75% if both parents are allergic (16). There are only a few published studies using the FDLQI questionnaire to estimate the QoL of patients' families for other dermatitis. Majority of reviewed articles measured the severity using SCORAD, in this study simplified version TIS index was used (17,18). The impact of many skin diseases is not limited to the patient but may extend to the rest of the family (19). Family members play a central role in the care of such patients, especially those with inflammatory skin disease, and so family impact data are potentially important components of the measurement of the overall burden of skin disease. In dermatology, measurement of this secondary impact of skin diseases on the patients family members has largely been ignored except for atopic dermatitis. Families may not get the level of psychosocial support that they need, further affecting and economic outcomes (20).

In this study the score ranged from 0 to 26 (mean: 16.64) reflecting moderate family impact, in , other studies reported less impact on the family quality of life (20,21,22,23). AD impact varies among families, to be moderate in 53%, severe in 31%, small impact in 11% and normal in 5%. Al shobili (24), reported comparable finding were 66.4% of families in his studies reported moderate impact, 6.9% reported severe impact on their life quality. Three clinical signs provide the best measure of current disease severity from the patient's perspective: excoriations, erythema, and edema /papulation. Excoriations provide a visual reflection of pruritus, and erythema and edema/papulation reflect acute inflammation (17). In this study each item of the severity index significantly affect the severity, but excoriation was the most factor that affect the total score. Excoriation are erosions as a result of scratching which sometimes lead to bacterial colonization. Excoriation also negatively affect the,ki8 sleep in children which consequently affect the parents quality of life ](17). The severity score was not significant differences among different gender, age groups and history of atopy.

The impact of many skin diseases is not limited to the patient but may extend to

the rest of the family (19). Globally, the results showed a strong association between QoL and disease severity, measured by different objectives, as already shown by international literature (25,26,27). In the current study correlational analysis was performed between FDLQI and disease severity evaluated with TIS index. The results of this study indicated that quality of life was significantly more disturbed with increasing severity of the disease. It has been shown that increased disease severity was associated with a greater impairment in QoL. In fact, the study found that a bad skin condition was significantly associated with a poorer child QoL and with a significant worsening of family's QoL, evidencing how AD tends to affect the whole family system and not only the individual patient. This observation is supported by results from other studies which claim that the family's quality of life is correlated to the severity of AD, with more severe cases associated with increased disruption of family functions (28,29,30,31). There were no significant differences in families quality of life score regarding the gender and the age of the child, in contrast the study of Campos et al (32) showed that the average QoL score was higher in younger children compared with older children. Regarding gender effect other studies revealed that, the quality of life of families of female patients is more severely affected than that of male patients parents of girls with AD had higher probability of experiencing low QoL than parents of boys with AD were (21,24). The quality of life showed a significant association with family's educational level. In this study families with education beyond secondary (fathers and mothers) were more severely affected, in contrast Al shobili (24), recorded parents with secondary education were more severely affected by the disease.

### **Conclusion**

The findings of this study have demonstrated the value of looking at the quality of life patient's families. AD appeared to have a moderate impact on the QoL of the enrolled families and FDQLI was significantly more disturbed with increasing severity of the disease and parent's education level. Extra expenditure, people reactions, burden of care and emotional impact were the most factors showing the greatest impact caused by the presence of AD child in the family. To the best of our knowledge, this is the first to be reported in Libya and North Africa.

**Ethical Clearance:** From the Ministry of health and Environment/ scientific committee.

### **Consent**

Written consent and right of withdrawal and ensuring confidentiality were issued for every family member attending with the patient.

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**Table.1: Classification of FDLQI scores.**

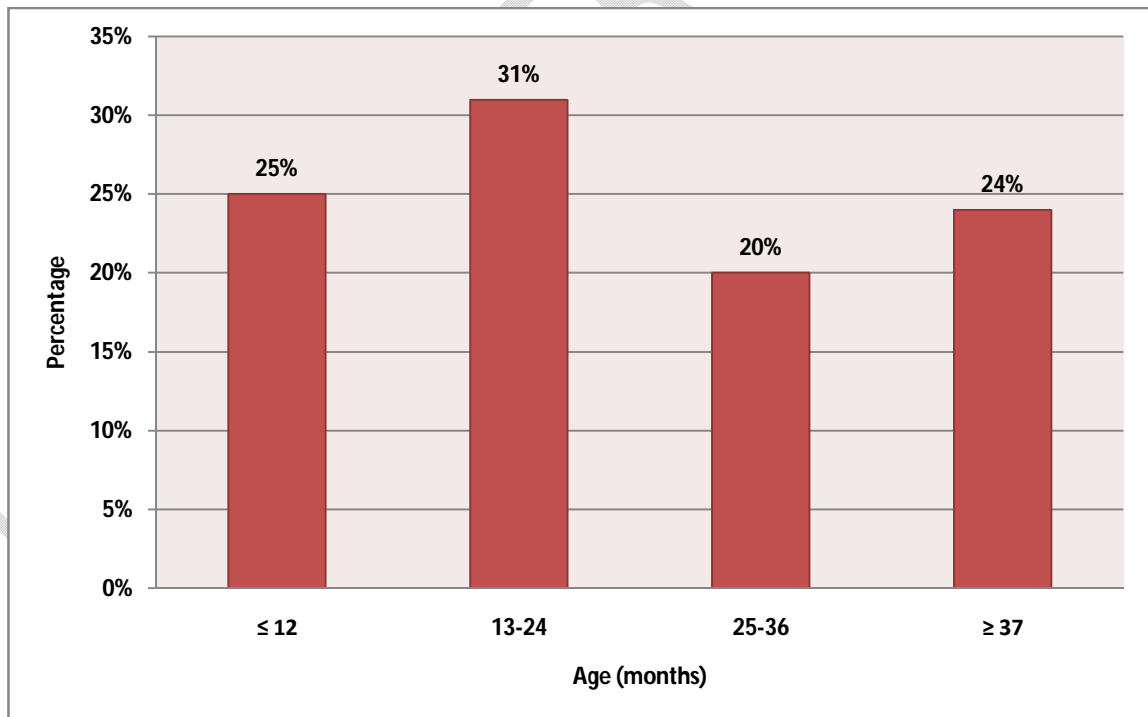
Classification	Score
Normal life	0 – 10
Low impact	6 -10
Moderate impact	11 – 20
High impact	➤ 20

**Table (2): Family Dermatology Life Quality Index score distribution**

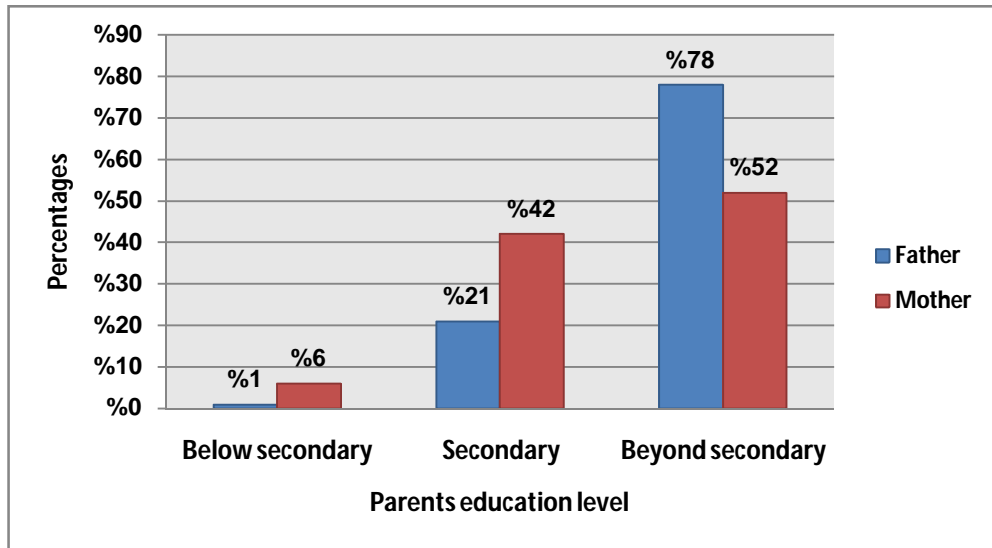
Questions	Not relevant	A little	Quite alot	Very much	Mean score ± STD
	%	%	%	%	
Emotional	2%	14%	37%	47%	2.29 ± 0.782
Physical well-being	4%	28%	44%	24%	1.88 ± 0.819
Relationships	42%	38%	20%	-	0.78± 0.759
People reactions	2%	6%	43%	49%	2.39± 0.695
Social life	17%	36%	41%	6%	1.36± 0.835
Leisure activities	26%	44%	28%	2%	1.06± 0.789
Burden of care	2%	11%	36%	51%	2.36± 0.759
Extra housework	26%	39%	33%	2%	1.11±0.815
Job/Study	41%	40%	18%	1%	0.79± 0.769
Extra expenditure	2%	11%	32%	55%	2.4± 0.765

**Table (3): Compare FDLQI among age groups.**

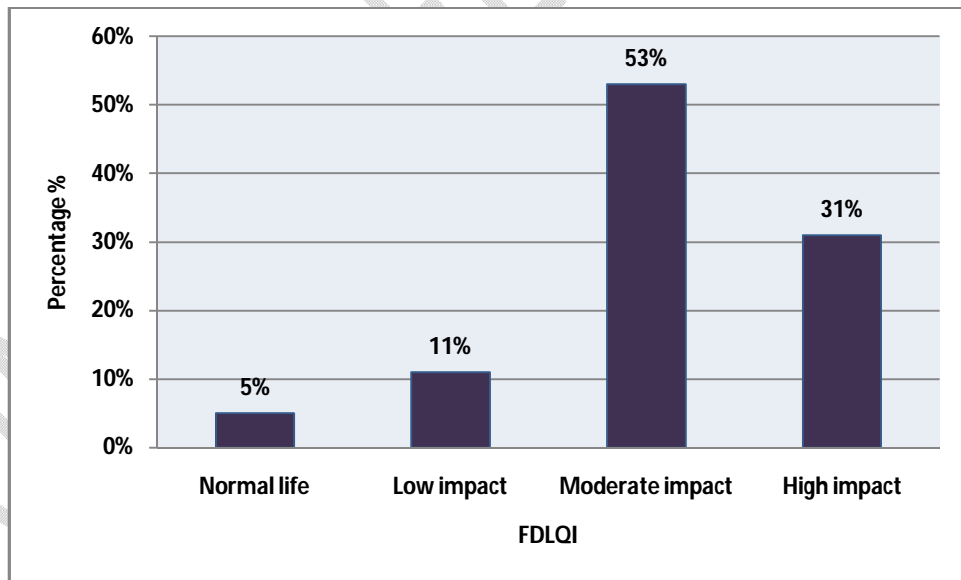
Age	N	Mean $\pm$ STD	ANOVA (Sig.)
$\leq 12$	25	15.8 $\pm$ 6.745	0.391
<b>13-24</b>	31	17.87 $\pm$ 5.445	
<b>25-36</b>	20	16.25 $\pm$ 5.25	
$\geq 37$	24	15.5 $\pm$ 5.794	
<b>Total</b>	100	16.46 $\pm$ 5.837	



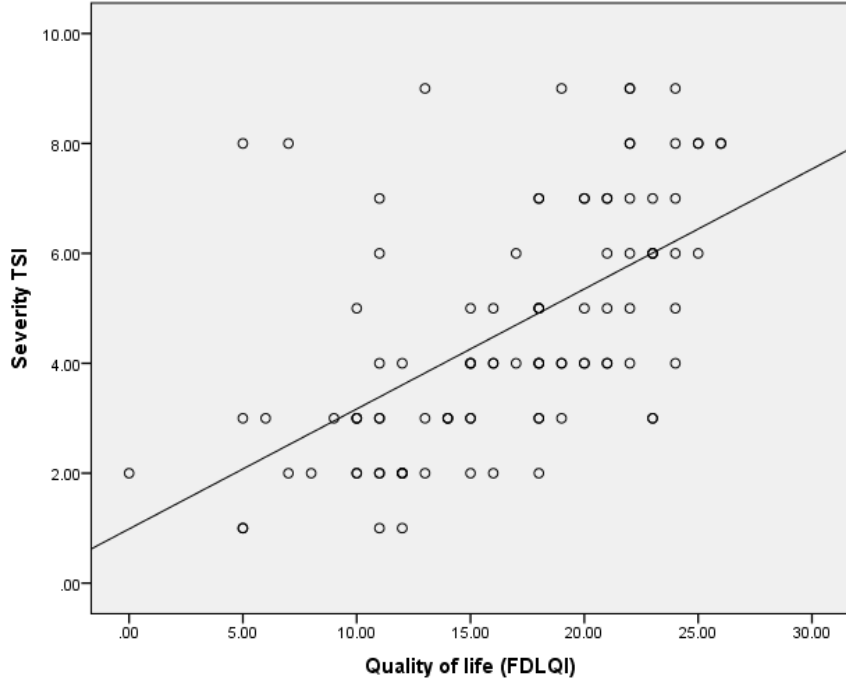
**Figure. 1: Distribution of subjects age (months).**



**Figure. 2: Distribution of parents according to their education levels.**



**Figure. 3: Distribution of families according to the quality of life.**



**Figure. 4: Impact of Dermatitis severity on FDLQI**

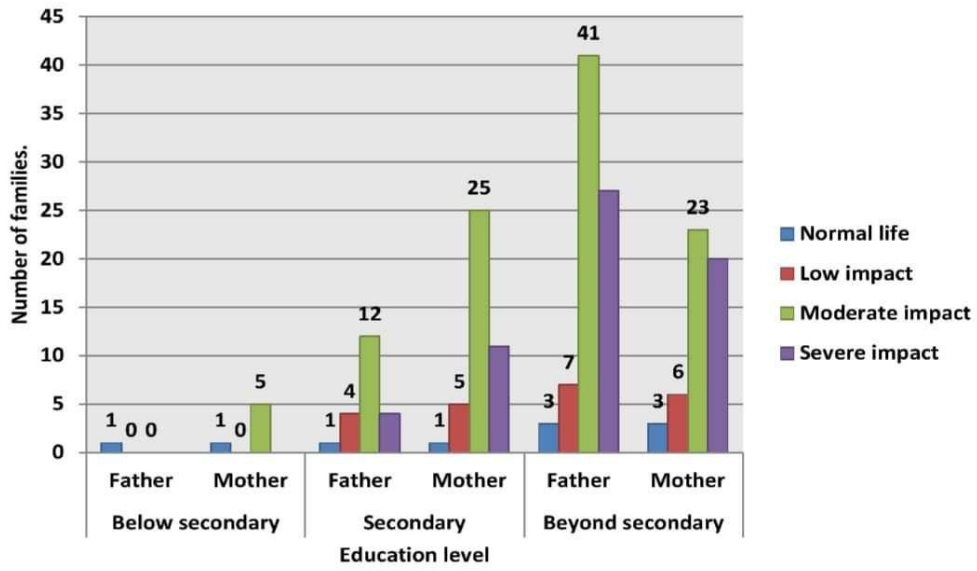


Figure.5: FDLQI according to parents education levels.