Original article

A study of health-related quality of life in pediatric atopic dermatitis

**Background:** Children of atopic dermatitis (AD) have difficulties in social adaptation and academic achievements. Health related quality of life (HRQOL) is a multidimensional measure not restricted to physical effects of disease or its treatment. **Objective:** We sought to assess, through validated questionnaire sets, the impact of AD on the HRQOL of children and their parents or caregivers. **Methods:** This analytical cross-sectional study was conducted on 85 children with physician diagnosed AD recruited from the Pediatric Allergy and Immunology Unit, Children's Hospital, Ain Shams University from May 2018 to December 2019. HRQOL of the patients was assessed using the Children’s Dermatology Life Quality Index (CDLQI) and that of parents/caregivers was assessed using the Family Dermatology Life Quality Index (FDLQI). **Results:** Analysing the CDLQI revealed that more than half of the studied sample (55.4%) had an extremely affected quality of life (QOL). The most affected physical aspects were itching and pain. There was statistically significant effect of face eczema on QOL of children. We also found that 65.9% of parents/caregivers had a significantly affected QOL score and the most frequently reported problems were emotional distress and treatment burden. The presence of other allergies in the affected child, other sib affection and adverse effects of treatment were the most significant distressing factors on the QOL of parents/caregivers. Poor QOL of children also impacted their parents’ mental and physical health. **Conclusion:** AD affects the QOL of both children and their guardians in many aspects. There is necessity to pay more attention to the psychological and social aspects in the children with AD and to respect their parents’ psychosocial impact and financial burden within the integrated management plans of AD.

Keywords: atopic dermatitis; children; CDLQI; FDLQI; Health Related Quality of Life; HRQOL; QOL.

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**INTRODUCTION**

Atopic dermatitis is a complex, chronic inflammatory skin disorder with significant morbidity. It is often a frustrating condition for both children and parents due to chronic and relapsing course.\(^1\) It is a complex immune mediated disease characterized by intense pruritus commonly beginning in childhood/infancy persisting or recurring in adulthood or presenting as adult onset disease.\(^2\,3\) The substantial public health impact of AD on population general health was established by the 2010 Global Burden of Skin Disease project and validated by the Cochrane Skin Group in 2014. In this context, skin diseases are considered the fourth leading cause of nonfatal disease burden among all chronic diseases. AD was particularly implicated as responsible for the greatest population-level disability.\(^4\)

Skin conditions have a negative impact on emotional status, social relationships and daily activities. Chronic pruritus is often untreatable, so it has a major impact on the QOL, as it affects the quality of sleep and children’s behaviour as well as their productivity. Parents of the affected children reported difficulties in discipline and in caring for their children.\(^5,7\) AD is associated with physical comorbidities, such as allergic rhinitis and asthma, which leads to more psychiatric comorbidities including depression up to suicidal thoughts. Patients with AD were noted 50 years ago to have a characteristic psychological profile, especially in anxiety and depression, that differs from patients with other cutaneous diseases.\(^8,9\)

A number of potential theories might explain the exact relation between AD and psychiatric illness. First, it is possible that changes in inflammatory markers contribute to psychiatric derangement. Second, there is a well-known link between sleep disturbance and depression in the general population. A number of studies noted an increase in sleep disturbances in patients with AD compared...
to non-atopic patients, which may contribute to an increased risk of depression. Third, pruritus which is a major symptom of AD is linked to depression and even suicidal ideation and the severity of itch is positively correlated with the severity of depression.10-13

QOL has gained extreme importance as an integrated part of the management of the chronic diseases. Children with chronic health conditions become physically, socially, and spiritually. Moreover, the negative impact of the chronic illness on the QOL extends from the children to their families.14-16 Improving HRQOL is a major goal in the management of chronic diseases. The study of QOL is an examination of influences upon goodness and meaning in life as well as people’s happiness and wellbeing.16,17

We sought to estimate, through validated questionnaires, the impact of AD on the quality of life of those children and their parents and/or caregivers. The ultimate objective is to outline the exact deleterious effects of AD on HRQOL and hence be able to design measures that would enhance the physical, social, psychological and spiritual lifestyles.

METHODS
This analytical cross-sectional study was conducted on 85 children with physician diagnosed AD and their caregivers. They were recruited from the Pediatric Allergy and Immunology Unit, Children’s Hospital, Ain Shams University during the period from May 2018 to December 2019. The study gained approval by the local ethics’ committee of the Department of Pediatrics, Ain Shams University. Informed consent was obtained from the parents or caregivers prior to enrollment.

We excluded children with concomitant chronic illness and/or significant social, medical or environmental problems unrelated to AD.

All children enrolled in the study were subjected to the following:
• Clinical evaluation including age, sex, socioeconomic status, family history of AD or atopy, presence of other allergies, frequency of outpatient clinic visits and frequency of exacerbations. Other data included age at onset, age at diagnosis, diagnostic lag, surface area affected and treatment received. Clinical examination was performed to assess the presence of any complications, active disease or other associated allergies.
• Patient and parent data were collected using individual questionnaires conducted by the investigator directed to the children and their caregivers.
• HRQOL was assessed using The Children’s Dermatology Life Quality Index (CDLQI) which consists of 10 items and covers symptoms and feelings, leisure, personal relationships, sleep, school and holiday info and treatment.
• Children were divided into two groups: group 1: aged 5 years and above who were able to answer the whole questions of the CDLQI questionnaire;18 and group 2: aged below 5 years. Parents/caregivers of group 2 were inquired for just 3 questions from the whole questionnaire which are questions about severity of itching; effect of the disease on the choice of their clothes and effect of the disease on their sleep, as the rest of the questions are not applicable for age.
• HRQOL for the parents/caregivers was assessed using The Family Dermatology Life Quality Index (FDLQI) which consists of 10 items and covers social, emotional and physical aspects as well as financial burden.19

Interpretation
For both CDLQI and FDLQI, each question was scored as follows:
- Very much = 3
- Quite a lot = 2
- Only a little = 1
- Not at all = 0

Total score ranges from a maximum of 30 and a minimum of 0:
- 0 and 1: no effect
- 2 to 6: small effect
- 7 to 12: moderate effect
- 13 to 18: very large effect
- 19 to 30: extremely large effect

Statistical Analysis
The collected data was revised, coded and tabulated and introduced to a PC using Statistical Package for Social Science (SPSS 13.0.1 for windows; SPSS Inc, Chicago, IL, 2001).
• Descriptive statistics: Mean and standard deviation (SD) for numerical data; frequency and percentages for non-numerical data.
• Analytical statistics: Student T test was used to assess the statistical significance of the difference between two study group means. Chi-square test was used to examine the relationship between two qualitative variables. Correlation analysis (using Pearson’s method): to assess the strength of association between two quantitative variables. The correlation coefficient denoted symbolically “r” defines the strength (magnitude) and direction (positive or negative) of the linear relationship
between two variables: \( r = 0-0.19 \) is regarded as very weak correlation, \( r = 0.2-0.3 \) is regarded as weak correlation, \( r = 0.4-0.59 \) is regarded as moderate correlation, \( r = 0.6-0.79 \) is regarded as strong correlation, \( r = 0.8-1 \) is regarded as very strong correlation.

**RESULTS**

This study was conducted on 85 children, aged between 1-14 years, 65 of them were above 5 years of age and 20 of them were below 5. Boys formed 76.5% and girls 23.5% of the studied sample. Most of the children had eczema in the face (89.4%), followed by the flexural sites (78.8%) and to less extent in the extensor surfaces (44.7%). Less than half of the patients had positive family history of atopy and 60% of them had personal history of other allergies including bronchial asthma, allergic rhinitis and food allergies (Table 1). All the children were on treatment, varying among topical emollients, topical corticosteroids and oral second-generation antihistamines. None of them were on systemic corticosteroids or immunosuppressants. Self-reported adverse effects of medications were more frequent in the older age group. (Table 2)

Upon analyzing the QOL of the children with AD according to CDLQI questionnaire we found that more than half of studied children had an extremely affected QOL (55.4%). The most common affected domains were the symptoms and feelings and leisure followed by sleep and personal relationship domains, while the least affected domain was school and holiday aspects (Figure1).

The main factors that had significant effect on children’s QOL were the face eczema, presence of other allergies and presence of self-reported adverse effects of treatment (Table 3). Most of our patients did not report adverse effects from the used medications; only 17 had itching and 17 suffered from skin infection and none of them had lichenification or disfigurement. However, the presence of adverse effects was associated with extreme alteration of the HRQOL. None of the studied children was using oral corticosteroids or immunosuppressants for treatment.

Upon analyzing the HRQOL scores of the families of the children with AD according to FDLQI questionnaire, we found that about two thirds of them had very large to extremely impaired QOL (65.9%), and 20% of them had moderate to small affection of their QOL. The QOL was not affected in only 14.4% of them. The most affected was the emotional domain (83.5%) followed by treatment burden (82.4%), physical domain (81.2%), time needed for care (80%), and social domain (78.8%) and the least affected were the personal relationships (62.4%); Figure 2.

The main factors that had significant effect on families’ QOL were: having other diseased sib, suffering of the affected child from other allergies and presence of self-reported adverse effects of medications used (table 4).

Noticeably, the HRQOL of the parents/caregivers was positively correlated to the QOL of their affected children meaning that the poor HRQOL of children may also impair their caregivers’ mental and physical health (figure 3).

**Table 1.** Site of AD lesions, history of allergy and rate of health care visits in the studied sample

| Site of lesions          | Face    | 76 (89.4%) |
|-------------------------|---------|------------|
|                         | Flexures| 67 (78.8%) |
|                         | Extensors | 38 (44.7%) |
| Family history          | Negative| 51 (60.0%) |
|                         | Positive | 34 (40.0%) |
| Other sib affection     | Negative| 62 (72.9%) |
|                         | Positive | 22 (27.1%) |
| Other allergies         | Negative| 34 (40.0%) |
|                         | Positive | 51 (60.0%) |
| Outpatient clinic visits (per 6 month) | Mean ± SD | 2.21 ± 2.03 |
|                         | Range   | 0-8        |

SD: standard Deviation
Table 2. Types and self-reported adverse effects of medications used in studied sample

| Treatment modality           | Use | Number | %   |
|-----------------------------|-----|--------|-----|
| Emollients                  | No  | 12     | 14.1% |
|                             | Yes | 73     | 85.9% |
| Non-sedating antihistamines | No  | 19     | 22.4% |
|                             | Yes | 66     | 77.6% |
| Topical corticosteroids     | No  | 46     | 54.1% |
|                             | Yes | 39     | 45.9% |

Adverse effects of topical treatment:
- Score 0: 47 (55.3%)
- Score 1: 19 (22.4%)
- Score 2: 19 (22.4%)
- Score 3: 0 (0%)

Score 0: no complications; score 1: itching; score 2: skin infection; score 3: lichenification/disfigurement

Table 3. Correlations between the demographic and clinical data of the AD children above 5 years of age and their HRQOL affection grades

| Data                        | No effect (no 5) | Small to moderate (no 7) | Very large to extreme (no 53) | Test  | P    |
|-----------------------------|------------------|--------------------------|-------------------------------|-------|------|
| Age (yr.)                   | Mean (SD)        | 7.80 (1.79)              | 7.36 (2.87)                   | 8.93 (2.71) | 3.062 | 0.216 |
|                             | Range            | 6 – 10                   | 5 – 13                        | 5 – 14 | 1.731 | 0.421 |
| Sex                         | Male             | 4 (80.0%)                | 4 (57.1%)                     | 42 ± 79.2% | 0.418 | 0.811 |
|                             | Female           | 1 (20.0%)                | 3 (42.9%)                     | 11 – 20.8% |
| Age of Onset (month)        | Mean (SD)        | 22.20 (10.31)            | 39.00 (51.47)                 | 22.53 (17.69) | 0.418 | 0.811 |
|                             | Range            | 12 – 36                  | 3 – 150                       | 1 – 84 |
| Diagnostic lag (month)      | Mean (SD)        | 3.60 ± 1.82              | 7.29 (7.83)                   | 12.49 (25.29) | 0.551 | 0.759 |
|                             | Range            | 2 – 6                    | 2 – 24                        | 1 – 120 |
| Site affection              | Face             | 2 (40.0%)                | 6 (85.7%)                     | 48 (90.6%) | 9.795 | 0.007* |
|                             | Flexures         | 5 (100.0%)               | 6 (85.7%)                     | 47 (88.7%) | 0.710 | 0.701 |
|                             | Extensor surfaces| 2 (40.0%)                | 2 (28.6%)                     | 26 (49.1%) | 1.127 | 0.569 |
| Family history              | Negative         | 2 (40.0%)                | 4 (57.1%)                     | 28 (52.8%) | 0.375 | 0.829 |
|                             | Positive         | 3 (60.0%)                | 3 (42.9%)                     | 25 (47.2%) |
| Other sib affection         | Negative         | 5 (100.0%)               | 5 (71.4%)                     | 34 (64.2%) | 2.735 | 0.255 |
|                             | Positive         | 0 (0.0%)                 | 2 (28.6%)                     | 19 (35.8%) |
| Other allergies             | Negative         | 5 (100.0%)               | 6 (85.7%)                     | 15 (28.3%) | 16.617 | <0.001* |
|                             | Positive         | 0 (0.0%)                 | 1 (14.3%)                     | 38 (71.7%) |
| Treatment                   | Antihistamine    | 4 (80.0%)                | 6 (85.7%)                     | 39 (73.6%) | 0.552 | 0.759 |
|                             | Emollient        | 4 (80.0%)                | 7 (100.0%)                    | 43 (81.1%) | 1.602 | 0.449 |
|                             | Topical steroids | 2 (40.0%)                | 2 (28.6%)                     | 24 (45.3%) | 0.725 | 0.696 |
| Adverse effects of treatment| Score 0          | 5 (100.0%)               | 6 (85.7%)                     | 20 (37.7%) | 11.956 | 0.018* |
|                             | Score 1          | 0 (0.0%)                 | 1 (14.3%)                     | 16 (30.2%) | 11.956 | 0.018* |
|                             | Score 2          | 0 (0.0%)                 | 0 (0.0%)                      | 17 (32.1%) |

SD: Standard deviation; * Significant
### Table 4. Correlations between the demographic and clinical data of the AD children and their families’ HRQOL affection grades

| Data                          | No effect | Small to medium | Very large to extreme | Test | P     |
|-------------------------------|-----------|-----------------|-----------------------|------|-------|
| Age (year)                    | Mean (SD) | Range           |                       |      |       |
| No. = 12                      | 5.04 ± 2.8| 2 – 10          | 7.56 ± 3.57           | 7.69 ± 3.4 | 5.981 | 0.05  |
| Test P                        | 0.778     | 0.678           | 0.1364                | 0.506 |       |
| Sex                           | Male      | Female          |                       |      |       |
| No. = 12                      | 8 (66.7%) | 4 (33.3%)       | 13 (76.5%)            | 44 (78.6%) | 0.778 | 0.678 |
| Age of Onset (month)          | Mean (SD) | Range           |                       |      |       |
| No. = 12                      | 22.3 ± 9.7| 12 – 36         | 28.29 ± 34.31         | 21.3 ± 17.4 | 1.364 | 0.506 |
| Test P                        | 0.228     | 0.892           | 0.228                 | 0.892 |       |
| Diagnostic lag (month)        | Mean (SD) | Range           |                       |      |       |
| No. = 12                      | 5.75 ± 6.21| 2 – 24          | 11.65 ± 20.74         | 11.0 ± 22.7 | 0.228 | 0.892 |
| Site of affection             | Face      | Flexures        | Others                |      |       |
| No. = 12                      | 9 (75.0%) | 9 (75.0%)       | 5 (41.7%)             | 52 (92.9%) | 3.360 | 0.186 |
| Test P                        | 0.513     | 0.774           | 0.228                 | 0.318 |       |
| Family history                | Negative  | Positive        |                       |      |       |
| No. = 12                      | 7 (58.3%) | 9 (52.9%)       | 35 (62.5%)            | 0.774 |       |
| Other sib affection           | Negative  | Positive        |                       |      |       |
| No. = 12                      | 11 (91.7%)| 15 (88.2%)      | 36 (64.3%)            | 6.272 | 0.043*|
| Test P                        | 0.513     | 0.774           | 0.228                 | 0.318 |       |
| Other atopy                   | Negative  | Positive        |                       |      |       |
| No. = 12                      | 8 (66.7%) | 10 (58.8%)      | 16 (28.6%)            | 9.113 | 0.010*|       |
| Test P                        | 0.513     | 0.774           | 0.228                 | 0.318 |       |
| Clinic visits (per 6 month)   | Mean (SD) | Range           |                       |      |       |
| No. = 12                      | 1.42 ± 1.38| 0 – 4           | 2.59 ± 2.50           | 2.27 ± 1.98 | 1.872 | 0.392 |
| Treatment                     | Antihistamine | Emollient | topical steroids     |      |       |
| No. = 12                      | 10 (83.3%)| 11 (91.7%)      | 15 (88.2%)            | 41 (73.2%) | 1.956 | 0.376 |
| Test P                        | 0.513     | 0.774           | 0.228                 | 0.318 |       |
| Adverse effects of treatment  | 0         | 1               | 2                     |      |       |
| No. = 12                      | 12 (100.0%)| 0 (0.0%)       | 0 (0.0%)              | 25 (44.6%) | 16.646 | 0.002*|
| Test P                        | 0.513     | 0.774           | 0.228                 | 0.318 |       |

SD: standard deviation; * Significant

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**Figure 1.** Frequency of HRQOL disturbance in the AD children
DISCUSSION
The highest negative effect on in our AD children above 5 years of age was related to itching and pain which had the greatest impact followed by sleep and personal relationship domains, while the least affected domain was that of school and holiday aspects. Most of the children in our series said that itching, pain and discomfort problems are badly affecting their lives. Similarly, itching, sleep disruption, mood shifts and feeling problems were reported in several studies to affect children’s QOL. Other problems related to AD, like compliance on treatment, dressing, relationship with friends and disordered playing and entertainment and weak self-confidence were also reported.

Among our series, 84.6% of the children believed that the disease had great impact on their relationship with friends, play and children recreations, while this was reported in only 2% by some other investigators. The difference may be attributed to social and cultural variations in different societies. As a matter of fact, symptoms such as itching and scratching can consequently aggravate AD lesions resulting in significant sleep deprivation leading to exhaustion, emotional swings and impaired functioning.

We observed a statistically significant effect of facial eczema in particular on the HRQOL. This
comes in agreement with data from other studies that displayed the bad impact of facial lesions on the QOL of children. The social interaction is expected to be worse in children with facial eczema due to poor acceptance of their peers or frequent comments on their looks.

Because not all domains of the CDLQI can be applicable to infants and children younger than 5 years, we could not thoroughly make comparative analysis according to age. However, three domains (symptoms and feelings, sleep and leisure) were studied in the young group and revealed statistically comparable data to those above 5 years. Some relevant studies concluded that the most negative effect on QOL was related to the mood and itching in the youngest age group (0–4 years old) compared to itching and leisure/hobbies in older children. Another group of investigators previously noted that the HRQOL mean score was more affected in younger than older children.

Data from the CDLQI questionnaire of 167 AD children, 5–16 years old, from Ukraine, Czech Republic, Singapore, and Italy were analyzed in a multicentre international study. Only in Czech children the overall CDLQI score was positively correlated with their age. Other reports did not find any significant association between child’s age and the QOL status due to AD. Amore recent publication reported that the QOL measured by CDLQI was more impaired in younger children, whilst child mood was more impaired in older infants. The most impaired QOL was seen in children in the age group 5–9 years. The authors concluded that treatment and counseling of children suffering from AD should be tailored specifically to their age. Study design variations as well as cultural and social factors may explain the difference between various reports.

In the current study, gender of patients had no effect on the HRQOL scores of parents and their families, which matches observations in some relevant studies. A gender effect might be expected in adolescents and those were not included in our series.

Only 45.9% of our patients were adherent to their topical corticosteroid prescription. Although adverse effects of topical corticosteroids are minimal when used appropriately, caregiver fears related to topical corticosteroids were commonly mentioned among our series. Patients with AD should be assured that topical corticosteroids are the mainstay of treatment and that their prompt use in the flare-ups is the optimal approach. Such education may lessen their concerns. A recent meta-analysis showed that health education improves SCORing Atopic Dermatitis (SCORAD) index of severity and quality of life as indicated by the Infants’ Dermatology Quality of Life Index. Indeed, promoting disease control through health education would improve the QOL.

AD had a profound impact on personal, social, emotional and financial perspectives of the children’s families in the current study. It was assumed by some investigators that the impact of moderate and severe AD on QOL of families was even greater than that of insulin dependent diabetes mellitus. Our data also show a strong relationship between affection of sleep in children and familial physical disturbances. This was similarly concluded in a study that explored the relationship between childhood AD and its impact on parents’ health. A strong relationship was found between disruption of sleep of the child and parental anxiety and depression. As parents spend hours to comfort their children and manage their disease, they need to be prepared mentally and physically to be able to adapt to the consequences of sleep disturbance, emotional distress, and exhaustion.

More than half of affected parents/caregivers in our series suffered very large to extremely affected HRQOL (65.9%), while 20% had moderate to small affection and about 14.1% declared no effect on their QOL. The most frequently reported problems were the emotional distress (83.5%) and treatment burden (82.4%); this can be explained by limited treatment expense coverage by medical insurance that in turn, increases the financial burden on the families. Physical effort and time needed for care (81% and 80% respectively), social (78.8%) and personal relationship domains (62.4%) were affected as well. Such impact on family life was previously noted by another group of investigators. In our study, emotional distress in parents was found to be among the highest scoring items of FDLQI domains while tiredness and exhaustion were moderately reported; findings that conform with some other publications. Family leisure activities and relationship between family members were the least affected items of FDLQI in our study; this was not the case in a relevant study. It seems that leisure activities are not among the priorities of the Egyptian families especially that all our cases belong to the low/middle socioeconomic sector of the community who seek health care at our almost free-of-charge medical facility.

We observed a significant impact of other sib affection, presence of other allergies in the affected
child and treatment adverse effects on the family’s QOL being more prevalent in parents with very large to extreme severity scores than those with no effect or less to moderate effect. It makes sense that families with more than one allergic member would experience greater QOL impairment due to compound treatment strategies and care-related tasks.

Noteworthy is that the QOL of the children with AD was positively correlated to their caregivers QOL and that poor HRQOL of children impaired their caregivers’ mental and physical health aspects. This can be rationalized by the great burden on the parents and caregiver because of the special patient needs, such as bathing, wet dressing, topical application, and household-related tasks and responsibilities like food restrictions, cloth selection, laundry, and house cleaning to avoid potential allergens; all are exhausting and time-consuming tasks. This combination of ongoing roles can have a profound effect on the QOL of caregivers.

The point of strength in this pilot study is that it explores the HRQOL of the Egyptian children suffering from AD knowing that relevant published data from our country on chronic diseases are very scant. First the sample size is limited and this hinders coming out with solid conclusions. Second, studied sub-groups are not equal and this is due to the consecutive enrolment of the subjects. This did not allow for accurate estimation of the influence of some variables such as the presence of other allergic disorders. A stratified non-random study design would be favorable in this aspect. Third, we did not include a healthy control group and this made us unable to analyze our results in respect to the quality of life of un-diseased Egyptian children and families living under similar socioeconomic circumstances.

In conclusion, although AD is not categorized as a life-threatening condition, it is indeed a disease that affects multiple domains of QOL beginning as early as in infancy and sometimes persisting throughout life. The QOL of the children with AD was positively correlated to their caregivers QOL and this indicates that evaluation of the QOL in atopic dermatitis should not be limited to measurement of its impact on the patient because the QOL of all family members is adversely impacted as well. This necessitates paying more attention to the psychological, social and spiritual aspects in the children with AD and caring about parents’ psychosocial and financial burdens as intimate parts of the management of AD. We recommend Wider-scale controlled studies on the QOL assessment of AD patients as well as health education programs to help patients and their families adapt to the physical and psychological challenges they face.

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