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Original Article

Impact of atopic dermatitis on quality of life in children and their families: A tertiary care hospital-based study from Northern India

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ABSTRACT

Objectives: Atopic dermatitis (AD) is a chronic inflammatory skin disease that is more frequent among children. Childhood is a critical time for physical and psychosocial development and AD develops more commonly in children in the first five years of life. The objective of the study was to determine the impact of AD on the quality of life (QoL) of Indian children and their families and correlate it with AD severity and the perception of severity as estimated by the family.

Material and Methods: In the present study, 30 children clinically diagnosed with AD and 30 age- and sex-matched healthy controls presenting to our hospital were evaluated. Data on QOL were obtained through a questionnaire; Infants Dermatitis Quality of Life Index (IDQOL), Children's Dermatology Life Quality Index (CDLQI), and Dermatology Life Quality Index (DQLI) were used for patients,and the Dermatitis Family Impact (DFI) questionnaire for the family of the patients. The severity of the disease was determined using the Scoring for AD (SCORAD) index.

Results: In our study, there were 16 male patients and 14 female patients. History of atopy was significantly higher in children with AD ($p < 0.001$); 13 patients had mild, 17 had moderate, and none of the patients had severe disease. The severity of the disease was found to correlate negatively with the age of the child. IDQOL positively correlated with the age of children with AD ($r = 0.865$, $P < 0.001$). CDLQI negatively correlated with the age of children with AD ($r = -0.616$, $P = 0.033$). Impairment in IDQOL and CDLQI showed a significant positive correlation with DFI ($r = 0.846$, $P < 0.001$; $r = 0.910$, $P < 0.001$).

Conclusion: AD is associated with lowered QOL of the patient,which increases with the severity of the disease. Itch and sleep disturbance were the most severely affected symptoms of AD. The disease significantly impacted the QOL of the family. The main issue with parents caring for AD children is continuous expenditure on treatment, emotional distress, and physical exhaustion. Therefore, efforts are needed to help parents by medical care personnel so that the outcomes in both the child and the significantly burdened parent caregiver can be improved.

Keywords: Atopic dermatitis, Scoring for atopic dermatitis index, Infant's dermatitis quality of life index, Children's dermatology life quality index, Dermatitis family impact questionnaire

INTRODUCTION

Atopic dermatitis (AD) is a common chronic inflammatory skin disease that is more frequent among children. Most of the children develop the disease in infancy (60% of patients), and onset before five years of age is seen in up to 85% of patients.[1,2] It is a multifactorial disorder, of which the most important component is the genetic predisposition of the patient modulated by environmental factors, infections and irritants,and exposure to allergens.[3] The diagnosis of AD is made clinically, using the Hanifin and Rajka diagnostic criteria.[4] The severity of the disease is measured based on a constellation of signs and symptoms using the Scoring for Atopic Dermatitis (SCORAD) index.[5] The psychological, physical, and social impact of AD is complex and affects both the patients and their families, significantly compromising their overall quality of life (QOL) [6] and this impact on the QOL may be linked to the severity of the disease.[7] There is a paucity of studies assessing the extent of these disturbances in Indian children. Therefore, this study was planned to assess the impact of AD on the QOL of patients and their families and to correlate with the severity of the disease.

MATERIAL AND METHODS

This was a case–control study conducted in a tertiary care hospital in Delhi over a year. The study was conducted after

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obtaining clearance from the Institutional Ethical Committee of our hospital and written informed consent was taken from each subject. A total of 60 children including 30 patients with clinically diagnosed AD and 30 age- and sex-matched healthy control subjects, attending the outpatient department were recruited.

A detailed clinical and QOL assessment was done for all the patients after taking written informed consent and details were entered in predesigned case record form. Severity of the disease was assessed for each patient using the SCORAD index.[5] Detailed, structured, and validated questionnaires were used (after taking permission) to assess the QOL of patients. Infant's Dermatitis Quality of Life Index (IDQOL), Children's Dermatology Life Quality Index (CDLQI), and Dermatology Life Quality Index (DQLI) were used for patients and the Dermatitis Family Impact (DFI) questionnaire for the family of the patients.[8-11]

Statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS) software version 21.0. Baseline data was presented as mean (standard deviation), median (interquartile range), or number (percentage) as appropriate. An unpaired *t*-test was applied to compare quantitative variables. A Chi-square test was applied to compare qualitative variables. Pearson's Chi-square and Spearman's Chi-square coefficients were used for correlation. $P < 0.05$ (confidence interval [C.I.] = 95%) was taken as statistically significant and $P < 0.01$ (C.I. = 99%) was taken as statistically highly significant.

Table 1: Disease characteristics among cases and healthy controls.

	Group A	Group B	*P*-value
Age	4.33±2.12	4.80±2.13	0.218
Socioeconomic class			
Upper lower	4 (13.3)	2 (6.7)	
Lower middle	12 (40)	11 (36.6)	0.809
Upper middle	13 (43.3)	15 (50)	
Higher	1 (3.3)	2 (6.7)	
Antenatal illness			1.00
Gestational hypertension	1 (3.3)	0	
Gestational diabetes mellitus	1 (3.3)	1 (3.3)	
Delivery			1.00
Vaginal	27 (90)	28 (93.3)	
Cesarean	3 (10)	2 (6.7)	
Birth weight			
Mean	2.3±0.83	2.6±0.75	0.896
Weight<2.5 kg	7 (23.3)	4 (13.3)	0.107
Gestational age			0.424
Pre-term	4 (13.3)	2 (6.7)	
Term	25 (83.3)	28 (93.3)	
Post-term	1 (3.3)	0	
Birth order			0.745
1	19 (63.3)	15 (50)	
2	9 (30)	10 (33.4)	
3	1 (3.3)	3 (10)	
4	1 (3.3)	1 (3.3)	
5	0	1 (3.3)	
History of atopy			
Self	12	1	<0.001
Family	6	2	0.021

RESULTS

Thirty patients of clinically diagnosed AD (Group A) and an equal number of age- and sex-matched control group patients (Group B) were studied. Out of the total 30 patients of AD, group A1 comprised 18 cases (6 males and 12 females) in the age group 0–4 years, and group A2 comprised 12 cases (10 males and two females) in the age group 5–11 years.

Among cases and control group, socioeconomic (SE) status, history of antenatal illness in the mother, mode of delivery (vaginal or cesarean section), birth weight, gestational age, birth order, and breastfeeding were statistically non-significant. A history of atopy was present in 18 (60%) cases in Group A, as compared to 3 (10%) controls in Group B, which was found to be highly significant ($P < 0.001$). The mean age of Group A was 4.2 ± 2.12 years (range 1–11) and that of Group B was 4.80 ± 2.13 years (range 2–10) [Table 1].

All the patients included in the study fulfilled at least three major and three minor criteria of the Hanifin and Rajka criteria for diagnosis of AD. The major criteria: pruritus, typical morphology and distribution of lesions, chronic or chronically-relapsing dermatitis, and personal or family history of atopy were present in 30 (100%), 23 (76.7%), 24 (80%), and 18 (60%) cases, respectively. All four criteria were fulfilled by 20 (66.7%) cases and 10 (33.3%) fulfilled three of them. Among the 23 minor criteria, the most common finding was xerosis which was seen in all the patients. This was followed by ichthyosis, palmar hyper-linearity, or keratosis pilaris which were noted in 25 (83.3%) and raised immunoglobulin (Ig) E levels in 25 (83.3%); [Table 2]. In Group A, 24 (80%) had raised AEC as compared to 3 (10%) controls in Group B. The mean AEC in cases with mild and moderate AD was 629 ± 238.44 and 950 ± 218.76, respectively ($P = 0.041$). AEC also showed a strong positive correlation with the severity of disease as measured by SCORAD ($r = 0.734$, $P < 0.001$).

The mean SCORAD value of Group A was 25.8 ± 4.94 (range 19–38). According to the grading of SCORAD, 13 patients had mild AD (SCORAD <25), 17 patients had moderate severity disease (SCORAD 25–50), and none of our patients had severe disease. The severity of the disease was found to correlate negatively with the age of the child. The disease was more severe in the younger age group ($r = -0.447$, $P = 0.013$). Out of the total five cases of infantile AD, 4 (80%) had moderate AD and 1 (20%) had mild disease. Among the 25 cases of juvenile AD, 14 (56%) had moderate severity disease while 11 (44%) had mild disease. A positive correlation between the socioeconomic (SE) class and SCORAD showed that patients

belonging to higher SE classes had greater disease severity (r = 0.520, $P = 0.003$).

The mean IDQOL score of the Group A1 was 12.3 ± 2.32 (range 6–16). IDQOL positively correlated with the age of children with AD (r = 0.865, $P < 0.001$). The highest scores, which were the variables that most negatively impacted the QOL, were "itching and scratching" (1.7 ± 0.42), "the child's mood" (1.3 ± 0.46) and "time to get the child to sleep" (1.2 ± 0.51), whereas the lowest-scored item was "problems in taking part in family activities" (0.8 ± 0.32); [Table 3].

The total mean CDLQI score of the Group A2 was 9.7 ± 2.49 (range 5–15). The CDLQI negatively correlated with the age of children with AD, with higher impairment in the younger children (r = −0.616, $P = 0.033$). The highest mean scores were "itchy, scratchy, sore or painful" (1.7 ± 0.42), "embarrassed, self-conscious, upset or sad due to the skin" (1.2 ± 0.45), and "problem with sleep" (1.1 ± 0.28), while the variable with the lowest score was "changing clothes/shoes according to disease"(0.5 ± 0.52); [Table 4].

Amongst the 18 cases in Group A1, mean DFI score was 11.7 ± 2.32 (range 7–15). DFI with the highest mean scores was "expenditure" (1.8 ± 0.32), emotional distress (1.6 ± 0.51), and tiredness/exhaustion of the main career (1.6 ± 0.48). The least scored item was "effect of diseases on relationship between family members" (0.94 ± 0.42). The impairment in IDQOL showed a significant positive correlation with DFI (r = 0.846, $P < 0.001$). Among the 12 cases in Group A2, mean DFI score was 8.9 ± 2.01 (range 6–13). Highest mean scores were "expenditure" (1.7 ± 0.38), emotional distress (1.2 ± 0.62), and tiredness/exhaustion of the main career (1.2 ± 0.38). The least scored item was "effect of diseases on relationship between family members" (0.2 ± 0.45). The impairment in CDLQI showed a significant positive correlation with DFI (r = 0.910, $P < 0.001$); [Table 5].

IDQOL correlated significantly with the severity of disease, with higher impairment being evident with greater disease severity (r = 0.765, P < 0.001). CDLQI also correlated with disease severity, with the higher impairment being observed in greater disease severity (r = 0.802, $P = 0.002$). DFI of Group A1 and Group A2 correlated significantly with the severity of disease in both groups (r = 0.702, $P = 0.001$, r = 0.842, $P = 0.001$).

Table 2: Diagnostic criteria as fulfilled by the patients.

Major Criteria	***n* (%)**
Pruritus	30 (100)
Chronic or chronically-relapsing dermatitis	27 (90)
Typical morphology and distribution	23 (76.7)
Personal or family history of atopy	18 (60)
Minor Criteria	***n* (%)**
Xerosis	30 (100)
Ichthyosis, palmar hyperlinearity, or keratosis pilaris	25 (83.3)
Raised serum IgE	23 (76.7)
Course influenced by environmental or emotional factors	23 (76.7)
Perifollicular accentuation	16 (53.3)
Intolerance to wool and lipid solvents	14 (46.7)
Cheilitis	12 (40)
Orbital darkening	11 (36.7)
Tendency toward cutaneous infections or impaired cell-mediated immunity	10 (33.3)
Dennie-Morgan infraorbital fold	10 (33.3)
Pityriasis alba	9 (30)
Facial pallor or facial erythema	8 (26.7)
Anterior neck folds	6 (20)
Itch when sweating	6 (20)
Early age of onset	5 (16.7)
Food intolerance	2 (6.7)
White dermographism or delayed blanch	2 (6.7)
Immediate skin-test reactivity, nipple eczema, keratoconus, and anterior subcapsular cataracts	0

IgE: Immunoglobulin E, *n*: Number of patients.

Table 3: Infants' Dermatitis Quality of Life Index scores of group A1 (0–4 years).

Question no.	Item description	Mean±SD
1	Itch	1.7±0.42
2	Mood	1.3±0.46
3	Time to sleep	1.2±0.51
4	Sleep disturbance	1.0±0.34
5	Playing/swimming	1.0±0.53
6	Family activities	0.8±0.32
7	Mealtimes	1.0±0.34
8	Treatment	1.0±0.23
9	Dressings/undressing	1.1±0.46
10	Bathtime	1.2±0.51
	Mean score	12.3±2.32

SD: Standard deviation.

Table 4: Child Dermatology Quality of Life Index scores of group A2 (5–16 years).

Question no.	Item description	Mean±SD
1	Itch	1.7±0.51
2	Embarrassment	1.2±0.45
3	Friendships	0.8±0.38
4	Clothes/shoes	0.5±0.52
5	Leisure/hobbies	0.9±0.19
6	Swimming/sports	0.6±0.49
7	Schools/holidays	0.9±0.28
8	Teasing/bullying	0.7±0.65
9	Sleep	1.1±0.28
10	Treatment	1.1±0.29
	Mean total score	9.7±2.49

SD: Standard deviation

DISCUSSION

In the present study, more than 80% of AD patients belonged to the middle-income group. Most of the Indian studies were conducted in tertiary care government hospitals that cater mainly to the patients from the lower and the middle SE classes and this might have been the reason for the predominance of AD in the middle classes.[12] The association between breastfeeding and the risk of AD is controversial with multiple studies analyzing the cause-effect relationship.[13] However, we found no significant association between the timing of initiation of breastfeeding, duration of exclusive breastfeeding, timing of introduction of solid food, and total duration of breastfeeding ($P > 0.05$). Health-related QOL is an outcome that extends beyond traditional views of mortality and morbidity and includes the health dimensions of symptoms, the functional effect of disease, and the broad psychological, social, and emotional effects of disease.[2] Although the effects of AD on children and their families have been studied in many countries, the specific impact of AD on the QOL of young children and their families has not been investigated in India. There is only a single study by Sarkar and Kanwar that assessed the psychological disturbances in Indian children with AD and their mothers. The study included 22 AD patients (aged 3–9 years) and their mothers with matched controls showed an increased prevalence of psychological disorders in Indian children with AD as compared to controls. It was also reported that more mothers of children with AD were submissive, which could contribute to the psychological disorders and maintenance of eczema in the children. Apart from this study, there are no other studies in Indian literature on the impact of disease on patients and families of AD.[14]

The mean total IDQOL score for AD (12.3 ± 2.32) was higher than the majority of the other international studies which include a study by Ricci *et al*.[7] from Italy (10.2), Beattie and Lewis-Jones[11] from UK (7.9), Xu *et al*.[15] from Singapore (8.76) Gånemo *et al*.[16] from Sweden (8.6), and much higher than that of Chinn *et al*.[17] from UK (5.8). This is surprising, especially due to the relatively lesser severity of disease in the Indian population,and can probably be explained by the overrating of the disease by the mothers in our setting. Further, the mean IDQOL score of cases of moderate AD was significantly higher than previous western studies, in mild AD ($P = 0.026$).[6,11,15-19] Similar to other studies, the IDQOL item with the highest score was itching and scratching.[7,8,15-19] The mean score for parental assessment of disease severity in the IDQOL was 2.3 ± 0.57 (range 1–3). It correlated positively with the severity of the disease as measured by SCORAD ($r = 0.367$, $P = 0.018$). This finding is important for the treatment of AD, as it is important for parents to understand adequately the magnitude of the severity of the disease that will ensure proper care and compliance with treatment.

The total mean CDLQI score was 9.7 ± 2.49 (range 5–15). This was higher than the study conducted by Holm *et al*. (7.15).[20] CDLQI showed a significant positive correlation with SCORAD, with higher impairment in greater disease severity ($r = 0.802$, $P = 0.002$); this is in concordance with the results of the previously reported studies.[9,16,17,19] Itch, problems with treatment,and sleep were the three most significantly affected QOL issues. Problems with friendship, school/holidays, and teasing/bullying only occurred in a minority of the patients. It was observed that CDLQI negatively correlated with the age of children with AD, with higher impairment in the younger children ($r = -0.616$, $P = 0.033$). Childhood AD affects the emotional, financial, physical, and social well-being of parents.[21,22] The impairment in IDQOL and CDLQI showed a significant positive correlation with DFI ($r = 0.846$, $P < 0.001$, $r = 0.910$, $P < 0.001$). The impact of AD on families of both groups positively correlated with its severity, with more severe cases associated with increased family disruption ($r = 0.702$, $P = 0.001$, $r = 0.842$, $P = 0.001$). The three items in the DFI with the highest mean scores were "expenditure," emotional distress, and tiredness/exhaustion of the main carer. A study conducted by Handa *et al*.[23] over 6 months, in 2015 showed that the cost of treatment of AD was about 25% of the total earnings for the period. Since most of the patients belonged

Table 5: Family Dermatitis Impact Questionnaire scores of group A1 (0–4 years) and Group A2 (5–16 years).

Item description	Group A1 (Mean±SD)	Group A2 (Mean±SD)
1. Housework	1.2±0.38	1±0.00
2. Food preparation/feeding	1.1±0.42	0.9±0.00
3. Sleep of others in family	1.1±0.64	0.8±0.29
4. Family leisure activities	0.7±0.46	0.5±0.52
5. Shopping for the family	0.4±0.51	0.7±0.75
6. Expenditure	1.8±0.32	1.7±0.38
7. Tiredness/exhaustion	1.6±0.48	1.2±0.38
8. Emotional distress	1.6±0.51	1.2±0.62
9. Relationships	0.94±0.42	0.2±0.45
10. Affect on main career	1.1±0.32	0.8±0.28
Mean total score	11.7±2.32	8.9±2.01

SD: Standard deviation.

to lower- and middle-class income groups, the financial burden of caring for a child with AD is significant. This is also a major reason for dropping out of treatment and non-compliance. This shows the great need to identify and offer counseling to the individual children as well as their parents suffering from the mental and psychological effects of AD in order to optimize the management of these patients.

Limitation

The limitations of this study include: a small sample size;results were obtained by evaluating children of different ages with a wide range of disease severity (some with remissions, others with exacerbations) that affect the response to the questionnaire, thus affecting the outcome. The study was conducted in a hospital setting; therefore, it may not represent the disease's impact on the general population. More studies on larger cohorts should be undertaken to better understand the impact of disease on children as well as the family.

CONCLUSION

AD is found to be associated with lowered QOL of the patient, with higher impairment seen in greater severity of the disease. This study illustrates that not all aspects of QOL are affected equally. Itch and sleep disturbance were the most important symptoms of AD and the most severely affected. This highlights the need to ensure higher efficacy symptomatic treatment in addition to specific treatment for better management of AD. The age of the patient is an important factor in QOL issues with itch being particularly more troublesome in younger children. Doctors caring for children with AD must be sensitive to the problems pertinent to the patient's developmental stage. Regardless of disease severity, treatment, and counseling should be tailored and targeted for the patients based on their age. The disease also significantly impacted the QOL of the family and this correlated positively with the severity of the disease. Expenditure on treatment and emotional distress along with physical exhaustion that comes with caring for a chronically ill child were the main issues with the parents. Therefore, efforts are needed to help parents identify symptoms that need expeditious medical intervention by appropriate medical care personnel so that the outcomes for both the child and the significantly burdened parent or caregiver can be improved.

Ethical approval

The research/study was approved by the Institutional Review Board at University College of Medical Sciences.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

Dr. Deepika Pandhi is on the Editorial Board of the Journal.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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