

# Assessment of Quality of Life among Parents of Children with Atopic Dermatitis

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## ABSTRACT

**Background:** Atopic Dermatitis is a chronic disease that improves and remits with time. It may affect parental life style and parent-child relationship. 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. Objectives: To assess the Severity of AD in the children and quality of life in parents of children with AD. To analyse the relationship of severity and treatment of the disease on the quality of life in parents. **Methods:** The study comprised 50 children diagnosed with AD ranging in age from 6 months to 12 years as well as parents of these patients attending Paediatric Dermatology Clinic at Dermatology department, GGS Medical College, Faridkot from February 2017 to February 2018. The quality of life was quantified by the Dermatitis Family Impact (DFI) Questionnaire. Eczema Severity was assessed using SCORAD Index. These two parameters were evaluated on two occasions 12 weeks apart, meanwhile the patients were managed accordingly. **Results & Conclusion:** The mean SCORAD and mean DFI Score at the baseline was  $32.016 \pm 10.78$  and  $15.14 \pm 4.0$  respectively. These values decreased to  $16.494 \pm 6.62$  and  $12.08 \pm 3.34$  respectively, at the end of 12 weeks. SCORAD and DFI scores, showed positive correlation which was statistically significant ( $p=0.04$  at both visits), implying that quality of parental life is significantly correlated to severity of AD in the child. Hence, proper management of dermatological illnesses often requires combined evaluation and management of emotional factors as well.

**Keywords:** Atopic dermatitis children, Quality of Life, Parents, Assessment, DFI.

## INTRODUCTION

Atopic Dermatitis (AD) is an itchy, chronic or chronically relapsing inflammatory skin condition that often starts in early childhood.<sup>[1,2]</sup> The typical itchy rash is characterized by erythema, papules/papulovesicles which may become excoriated and lichenified, and has a flexural distribution.

Short term relief in skin symptoms is often obtained, but long term management can be frustrating and exhausting to the sick child as well to his/her parents. In addition to the skin symptoms, it may also cause anxiety, stress, behavioural problems, irritability, sleep dysfunction, and depression due to

the unsightly appearance of the skin, inability to express his/her emotions regarding the disease and discrimination by the peers and society, which all might lower quality of life of the child.<sup>[3,4]</sup> Besides, negative influences have been observed in families, such as feelings of inadequacy about their role as parents, concerns, frustration, fears about the disease, disappointments and self-blame.<sup>[5]</sup>

QoL is a wide concept, influenced by psychological state, physical health, level of independence and social relations. The World Health Organization (WHO) has defined Quality of life (QOL): 'The individual's perception of his position in life in the context of culture and value systems in which he lives and in relation to his goals, expectations, standards and concerns'.<sup>[6]</sup>

The literature on QoL has increased substantially over the past few years, whereas earlier, medical concerns were mainly focussed on issues such as prevention, cure, and costs. Impact on QoL includes all social, emotional and physical aspects of an

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individual's life which, in the case of pediatrics, affect not only the patient but also the family.

The physical, psychologic and social impact of atopic dermatitis is complex and varies among children of different ages, and the effects of atopic dermatitis on the quality of life of children and their families are not well understood. Thus understanding the emotional burden of a chronic disease such as AD is important for offering appropriate care. The aim of this study is to identify the areas of family life most affected and their correlation with the severity and treatment of the disease. The Dermatitis Family Impact (DFI) questionnaire was used for determining the ways in which lives of parents of children with AD were affected, while the severity of the disease in child was measured using SCORAD index.

## MATERIALS AND METHODS

### Study Area

Department of Dermatology, Venereology & Leprology at Guru Gobind Singh Medical College and Hospital, Faridkot, Punjab.

### Study population

Children diagnosed with AD ranging in age from 6 months to 12 years attending the Paediatric Dermatology Clinic at the dermatology department, GGS Medical College, Faridkot from February 2017 to February 2018.

### Inclusion Criteria

Children diagnosed with AD ranging in age from 6 months to 12 years using Hanifin and Rajka's diagnostic criteria of atopic dermatitis and their respective parents.

### Exclusion Criteria

Patients or siblings suffering from any significant medical condition such as epilepsy, mental retardation, alopecia universalis and cerebral palsy.

### Method

It was a prospective study comprising children diagnosed with AD (acute as well acute on chronic cases) ranging in age from 6 months to 12 years as well as parents of these patients attending Paediatric Dermatology Clinic at Dermatology department, GGS Medical College from February 2017 to February 2018. A total of 50 patients along with their respective parents were enrolled in the study. Consent was taken from all the participating Parents. Eczema Severity was assessed using SCORAD Index. The quality of life was quantified by the Dermatitis Family Impact (DFI) Questionnaire by verbally translating the questions into vernacular language of the subjects. These two parameters were evaluated on two occasions 12 weeks apart, meanwhile the patients were managed accordingly.

### Statistical Analysis

Various parameters studied were tabulated and means and standard deviations of different variables were calculated. t and paired t-tests were used to

compare the means within groups. Spearman's rho test was used to analyze correlation of SCORAD and DFI scores. The data was entered in the form of a data matrix in Microsoft Excel 2007 and analyzed statistically employing appropriate tests of significance using IBM SPSS® version 20.0.0 software at the end of the study period. P value < 0.05 was considered statistically significant.

## RESULTS

We studied 50 patients of atopic dermatitis along with their respective parents. Out of 50 patients [Table 1], 28 (56%) were males and 22 (44%) were females, ranging in age group of 6 months to 12 years. The most common chief complaint was pruritis seen in 15 (30%), xerosis in 11 (22%) followed by itching Scalp in 8 (16%), Lichenification in 7 (14%), papularurticaria in 5 (10%) and orbital darkening in 4 (8%) subjects.

In 39 (78%) subjects, carer (accompanying guardian) was mother and in 11 (22%) subjects, father. 21 (42%) subjects had personal history of atopy but was absent in 29 (58%) subjects. Family history of atopy was present in 31 (62%) subjects.

IgE levels were raised in 28 (56%) subjects. In the treatment part emollients were given to all the 50 patients (100%), antihistamines in 48(96%), topical steroid in 41(82%), oral steroids in 17(34%), topical immunosuppressants in 20(40%), oral immunosuppressants in 7 (14%) of subjects depending upon the severity of the disease.

Out of 50 patients, 12 (24%) had mild disease (SCORAD<25), 34(68%) had moderate (SCORAD 25-50) and 4 (8%) had severe (SCORAD>50) disease at the baseline. With the physician's intervention (treatment), depending upon the severity of the disease the spectrum changed to 44(88%), 6(12%),0(0%) subjects in mild, moderate and severe groups respectively, at the end of 12 weeks.

The initial mean of SCORAD for 50 children was  $32.01 \pm 10.78$  and with proper treatment the score reduced to  $16.46 \pm 6.62$  at the end of 12 weeks, representing a significant improvement in the severity of disease ( $p<0.05$ ).[Table 2]

The initial mean of DFI of parents of 50 AD children was  $15.14 \pm 4.00$  and 12 weeks later, it dropped to  $12.08 \pm 3.34$ , representing a significant improvement in the quality of life of parents ( $p<0.05$ ).[Table 3]

The changes in mean DFI scores were significantly related to changes in mean SCORAD scores ( $p<0.05$ ).

SCORAD and DFI scores, both at the baseline and at the end of 12 weeks showed positive correlations which were statistically significant ( $p=0.04$  at both visits), implying that quality of parental life is significantly correlated to severity of AD in the child at both baseline and at the end of 12 weeks.

The greatest impact was seen on the DFI domains assessing disturbed sleep (1.76,1.21), expenditure (1.76,1.72) and food preparation (1.72,1.54) on both the visits.[Table 4 & Figure 1]

The initial mean of DFI for 50 children was 15.14 ± 4.00 and 12 weeks later, it dropped to 12.08 ± 3.34, representing a significant improvement in the quality of life of parents (p<0.05).

**Table 1: Descriptive characteristics of the patients**

		Count	Percentage %
Total Patients		50	100.0
SEX	Male	28	56.0
	Female	22	44.0
Age	6 months - 5 years	38	76.0
	6 years - 12 years	12	24.0
Chief Complaints	Pruritus	15	30.0
	Xerosis	11	22.0
	Papularurticaria	5	10.0
	Itchy Scalp	8	16.0
	Peri Orbital darkening	4	8.0
	Lichenification	7	14.0
Carer	Mother	39	78.0
	Father	11	22.0
History of Atopy in family	Present	31	62.0
	Absent	19	38.0
IgE Levels	Raised	28	56.0
	Normal	22	44.0
Treatment Given	Emollients	50	100.0
	Antihistamines	48	96.0
	Topical steroids	41	82.0
	Oral steroids	17	34.0
	Topical Immunosuppressants	20	40.0
	Oral Immunosuppressants	7	14.0

**Table 2: SCORAD (Severity of Disease in Child)**

	Mean	S.D
SCORAD 1	32.016	10.783
SCORAD 2	16.494	6.627

Initial mean of SCORAD for 50 children was 32.01 ± 10.7 and 12 weeks later the mean reduced to 16.49 ± 6.62, representing a significant improvement in the severity of the disease (p<0.05)

**Table 3: Quality of Life Measurement (DFI Score)**

	Mean	S.D
DFI 1	15.14	4.00
DFI 2	12.08	3.34

**Table 4: Scores of each DFI domain at Baseline and at 12 weeks**

DFI and its Domains	DFI score (mean)	DFI Score (Mean)	% Reduction
Total DFI	15.14	12.08	20.2 %
Housework	1.47	1.20	19.3 %
Food	1.72	1.54	10.5 %
Sleep	1.76	1.21	31.3 %
Family Leisure activity	1.30	1.27	2.3 %
Time for shopping	1.2	1.1	8.3 %
Expenditure	1.76	1.72	2.2 %
Tiredness	1.40	1.32	5.7 %
Emotional distress	1.6	1.43	10.6 %
Relationship	0.7	0.67	4.5 %
Treatment	1.17	1.0	14.6 %

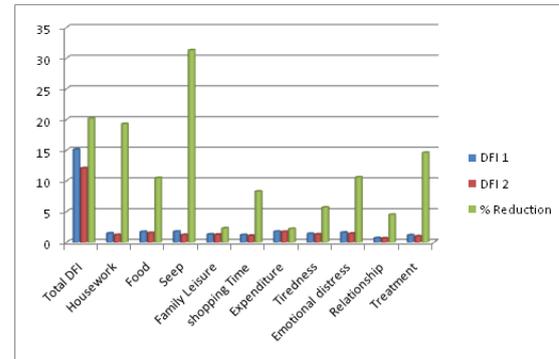


Figure 1: “Table 4 & Figure 1” shows the greatest impact is on the domains assessing disturbed sleep (1.76,1.21), expenditure(1.76,1.72) and food preparation (1.72,1.54) on both the visits. The lowest scoring domain is relationship between family members (0.7,0.67).With physician intervention the most improved domains are disturbed sleep of family members, help needed in treatment and housework.

## DISCUSSION & CONCLUSION

The impact of dermatological diseases on patients’ lives is often overlooked by not only health policy makers and insurance companies, but also by physicians and the general public. Because chronic skin diseases are often not life-threatening, attention and funds are usually diverted to diseases that are perceived as more serious. However, the psychosocial and occupational impact of cutaneous illnesses is frequently comparable to, if not greater than, other chronic medical conditions. These negative effects can ultimately compromise overall quality of life.

Unfortunately, for most of these patients, their psychiatric diagnosis stays unrecognized, overlooked and untreated. Due to the social stigma of psychiatric illnesses, patients prefer the treatment of their dermatological diseases rather than their psychiatric disorders. This results in immense somatic and psychic suffering, social and occupational dysfunction, poor academic performance, suicide, drug abuse, homicide, aggression, and an increase in mortality. Many studies have shown that these disorders have an important negative impact on the quality of life of the patient per se and the family involved.

The extra time consumed in the care of the sick child, efforts required for special food preparation, absenteeism from work for child care add to the agony of the parents as the child is unable take his/her own care. The concern of the parents about the prognosis of the disease, cost of treatment and social stigma attached to the unsightly appearance of the skin further adds to the suffering of the parents.

As children are unable to express their feelings regarding the disease as well as the discrimination they experience from the peers and society, there is a need to address the child's QoL and this impairment is poorly understood by level of sensitivity and understanding, the adults possess.

The child may express it in the form of anguish, poor grades in academics, irritability and asocial behaviour, which further adds to the parental stress. Thus, measuring the quality of life in parents, indirectly reflects the QoL of the affected child.

In the present study we assessed psychiatric morbidity and quality of life in parents of children with atopic dermatitis in relation to the severity of the disease in their child.

The reduction in both the scores (SCORAD and DFI) at 12 weeks after initiating the treatment highlights the fact that as the severity of disease in child decreases, the quality of parental life improves.

The present study showed no statistically significant difference in the severity of disease in male and female children ( $p=0.09$ ), though the mean SCORAD was higher in females. Similarly there was no statistically significant difference in parental quality of life depending upon the gender of the child ( $p=0.62$ ), though the mean DFI score was found to be more in parents of females.

The results were in contrast to a study by Jang et al who had mentioned that families of girls with AD had a lower QoL (OR, 8.40;  $p = 0.003$ ) than families of boys.<sup>[7]</sup>

We found that the severity of the disease was more in older children (age group 6-12 years) ( $p=0.02$ ). Though there was no statistically significant difference in the quality of life of parents of children across the two age groups ( $p=0.20$ ). The results being in accordance to a study by Robaee et al which reported that age of the atopic child had no impact on the quality of parental life.<sup>[8]</sup>

A study by Ben-Gashir et al reported atopic eczema to be more severe in children with asthma or hay fever.<sup>[9]</sup> Though, both the mean SCORAD and the mean DFI scores were higher in children with personal and family history of atopy, the results came out to be statistically insignificant (SCORAD :  $p= 0.62$  for personal history and  $p=0.52$  for family history ; DFI :  $p=0.20$  for personal history and  $p=0.06$  for family history).

Children with raised serum IgE levels had more severe disease as compared to the ones with normal levels ( $p=0.02$ ). Also the parental QoL was more impaired in children with raised serum IgE levels ( $p=0.01$ ). The results being comparable to a study by Nora et al which mentioned that serum IgE levels correlate with the degree of eczema in their study.<sup>[10]</sup>

The greatest impact was seen on the DFI domains assessing disturbed sleep (1.76,1.21), expenditure (1.76,1.72) and food preparation (1.72,1.54) on both the visits. The lowest scoring domain was relationship between family members. With

physician's intervention (treatment/counselling) the most improved domains were disturbed sleep of family members, help needed in treatment and housework.

Robaee et al in their study also showed similar results with food preparation, disturbed sleep and expenditure domains scoring the highest.<sup>[8]</sup>

Whereas studies by Ben-Gashir et al and Alvarenga et al reported disturbance in food preparation to be lowest scoring item. The difference could be due to different customs of food preparation between our country and the countries where these studies were conducted.<sup>[11,12]</sup>

The family leisure activity, time spent in shopping and relationship between family members were the least scoring domains in our study, in accordance with the results shown by Baettie et al.<sup>[13]</sup>

Our study had few limitations. The study population consisted of the patients reporting to our tertiary care hospital. The relatively small sample size and limited geographic location restricts the applicability of our findings to other populations. Thus, the data may lack representation from other places in the country as well.

Thus, the present study concludes that higher the severity of disease in the child, more impaired the quality of life of parents. This in turn may negatively impact child's health, as parents are the primary caregivers to their children.

The reduction in both SCORAD and DFI scores at the end of 12 weeks, highlights the fact that proper management by the physician can elate the morale of the anxious and depressed parents. Co-morbid depression may also adversely affect the management of the disease as it may lead to onset or aggravation of skin lesions, poor drug compliance and unnecessary doctor shopping. Hence, proper management of dermatological illnesses often requires combined evaluation and management of emotional factors as well. Counselling plays an important role in the management of chronic skin diseases, including atopic dermatitis. The population affected by the disease comprises of young children and the family/parents are the principal caregivers in this set of population. So, it is of immense importance to consider the psychological impact, the disease has on the parents due to their sick child and professional intervention should be recommended if deemed necessary. The study helped us to get better knowledge about the practical difficulties faced by the guardians of AD children, thus signifying the role of DFI questionnaire as a guide to explore the factors/domains affecting the QoL and managing them accordingly. Thus, the future strategies for chronic dermatological disorders, including atopic dermatitis should include 'the must counselling sessions' both for the patient as well as for the family as a part of management regimens rather than focussing solely upon the treatment of the disease.

Due to the overburdened OPDs in government setups and shortage of psychodermatology clinics, the needs of such patients and their guardians remain unmet. So, it is advisable to arrange special training sessions for the dermatologists to tackle the psychological problems of these individuals as well as appointment of skilled counsellors in dermatology clinics to aid the physician for the betterment of these patients and their families. Weekly or fortnightly joint sessions for the children and their families covering their medical, nutritional and psychological queries by a multi-professional team consisting of a treating dermatologist, a psychologist, a nutritionist and a skilled nursing assistant can be arranged especially in resource limited nations.

### **What is already known and what the study adds?**

#### **SUMMARY BOX**

Co-morbid depression may adversely affect the management of atopic dermatitis as it may lead to onset or aggravation of skin lesions, poor drug compliance and unnecessary doctor shopping. Hence, proper management of dermatological illnesses often requires combined evaluation and management of emotional factors as well.

The psychological impact, the disease has on the parents due to their sick child and professional intervention should be recommended if deemed necessary.

Knowledge about the practical difficulties of the guardians of AD children, thus signifying the role of DFI questionnaire as a guide to explore the factors affecting the QoL and managing them accordingly.

“The must counselling sessions” both for the patient as well as for the family as a part of management regimens.

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