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Impairment Quality of Life in Families of Children with Atopic Dermatitis

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SUMMARY Atopic dermatitis (AD) not only changes the life of the affected child but also affects the physical, social and emotional functioning of parents. The aim of the study was to assess the quality of life of parents of children with AD and to correlate it with the disease severity. It was a cross sectional, self-administered questionnaire study performed in parents of children with AD attending dermatology clinics affiliated to the College of Medicine, Qassim University, Saudi Arabia. The parents were asked to complete the validated Arabic version of the Dermatitis Family Impact (DFI) questionnaire. The severity of AD was evaluated by using the objective SCORAD index. Atopic dermatitis was considered mild when the score was <15, moderate at 15-40 and severe at >40. Out of a total of 774 children, 283 (36.6%) had mild, 259 (33.4%) moderate and 232 (30%) severe AD. The mean DFI score was 13.86±4.23. The DFI score of parents of children with severe AD (18.13±1.97) was significantly higher ($P<0.001$) as compared to mild (9.62±2.76) and moderate (14.68±2.26) AD. Family history of atopy in children and social class of parents had significant effect on the mean DFI scores. The highest scoring DFI domains were expenditure (mean score 1.74), sleep disturbance (mean score 1.73), food preparation (mean score 1.67) and emotional distress in parents (mean score 1.6). Tiredness and exhaustion in parents and housework were moderately affected, while the least affected areas were family leisure activity, treatment difficulties, time for shopping and relationship between family members. The severity of child's AD directly affects the quality of life of parents. The DFI is of value to guide appropriate management of children with AD and can be used as an added parameter in clinical trials concerning the management of children with AD.

KEY WORDS: atopic dermatitis, Dermatitis Family Impact (DFI) questionnaire, quality of life

Atopic dermatitis (AD) is a chronic inflammatory skin disease that often begins in infancy or early childhood, with 90% of cases appearing in the first five years of age (1,2). Itchy, dry skin combined with eczema lesions are the basic features of AD (3). Short-term improvement of the skin condition is often easily obtained, but long-term management can be frustrating for the child and his/her parents (4). Especially when severe, AD can be extremely disabling, causing major psychological problems in children and in case of a young child, the entire family can be distressed (5,6). Having a child with AD can have a detrimental effect on intimate and social relationships and the family may also bear a significant financial burden associated with AD (7). Atopic dermatitis not only changes the life of the affected child but also affects the physical, social and emotional functioning of his/her parents (8,9).

Understanding the emotional burden of a chronic disease is essential for offering appropriate care. While many parents cope more or less well with the situation, it is important to identify those for whom AD is associated with a pronounced adverse impact on their life (4). Many studies have reported the burden of childhood AD on their families (10-13). Lawson *et al*. (10) report that parents described a general burden of extra care and psychological pressures including feelings of guilt, exhaustion, frustration, resentment and helplessness. Carroll *et al*. describe parents of children with AD as suffering from high stress levels associated with treating and taking care of the child with AD, and feelings of helplessness regarding the child's symptoms (13).

Although the effects of AD on children and their families have been studied in many countries, to the best of our knowledge the specific impact of childhood AD on the quality of life of their parents has not been investigated in Saudi Arabia. The objective of this study was to assess the quality of life of parents of children with AD and to correlate it with the disease severity. The Dermatitis Family Impact (DFI) questionnaire was used for this purpose, which is a useful questionnaire to determine the ways in which the lives of parents of children with AD are affected (10).

MATERIAL AND METHODS

This was a cross sectional, self-administered questionnaire study performed during a six-month period from November 2009 to April 2010. Ethical approval was obtained from Ethics Committee of the College of Medicine, Qassim University. Out of a total of 814 families, 774 agreed to participate in the study. The response rate was 95%. Therefore, a total of 774 children aged 17-130 months with a diagnosis of AD fulfilling the criteria of Hanifin and Rajka (14) attending the dermatology clinics affiliated with the College of Medicine, Qassim University, Saudi Arabia, were enrolled in this study. The children with other major chronic comorbidities defined as psoriasis, vitiligo, asthma, diabetes mellitus, etc. that could affect the parents' quality of life different from AD were excluded from the study. The parents of children eligible for the study were introduced into the subject of the study and informed about the nature of the questionnaire. Those who gave their consent were asked to complete the validated Arabic version of the DFI questionnaire (15). The questionnaire consisted of 10 questions regarding the influence of the child's AD on his/her family in regard to housework, food preparation, sleep, family activities and entertainment, shopping time, expenditure, tiredness, emotional distress, relationship between family members and treatment. Each question was assigned a score from 0 to 3, with a maximum score of 30. The severity of AD was evaluated by using the objective SCORAD index (16). Atopic dermatitis was considered mild when the score was <15, moderate at 15-40 and severe at >40.

Means and standard deviations of different variables were calculated. Pearson χ^2-test was applied for categorical data and t-test was used to compare the means within groups. The values of $P<0.05$ were considered statistically significant. Statistical analysis was performed using SPSS version 17 software (Statistical Package for Social Science, version 17).

RESULTS

Table 1 shows demographic data and DFI score of study patients. A total of 774 children were enrolled. Out of these, 439 (56.7%) were males and 335 (43.3%) females. Their age ranged from 17 to 130 months, mean age 65.84±32.87 months. Family history of atopy was positive in 130 (16.8%) patients. Out of 774 children, 283 (36.6%) had mild, 259 (33.4%) moderate and 232 (30%) severe AD.

The parents of all 774 children completed the DFI questionnaire. The mean (±SD) DFI score was 13.86±4.23, range 5 to 21. The mean DFI score of parents of male and female children was 13.67±4.27 and 14.12±4.17, and of parents of children of young and older age groups 14.17±5.3 and 13.59 ± 3.13, respectively; data are summarized in Table 1. The mean (±SD) DFI score of parents of children with a positive and negative family history of atopy was 15.32±4.82 and 13.57±4.04, respectively, the difference being statistically significant ($P<0.001$). Parents belonging to low social class had a statistically significantly ($P<0.001$) higher mean DFI (±SD) score (16.5±2.9) as

Table 1. Demographic data and Dermatitis Family Impact (DFI) score of study patients

Characteristic	Number (%)	DFI score (mean ± SD)
Total patients	774 (100)	13.86 ± 4.23
Sex		
Male	439 (56.7)	13.67±4.27
Female	335 (43.3)	14.12±4.17
Age, mo		
Range	17-130	–
Mean ± SD	65.84±32.87	–
Young age group, mo	361 (46.6)	14.17±5.30
Range	17-63	–
Mean ± SD	34.43±14.63	–
Older age group, mo	413 (54.4)	13.59±3.13
Range	70-130	–
Mean ± SD	93.28±3.31	–
Family history of atopy		
Positive	130 (16.8)	15.32±4.82*
Negative	664 (83.2)	13.57±4.04
Education of parents		
Secondary	309 (39.9)	14.08±5.08
> secondary	465 (60.1)	13.71±3.56
Social standard of parents		
Low	103 (13.3)	16.5±2.9*
Average	490 (63.3)	13.38±4.56
High	181 (23.4)	13.66±3.32
Severity of AD		
Mild	283 (36.6)	9.62±2.76
Moderate	259 (33.4)	14.68±2.26
Severe	232 (30)	18.13±1.97*

% = percentage; mo = months; SD = standard deviation; > = more than; AD = atopic dermatitis; *$P<0.001$

compared to parents belonging to average and high social class (13.38±4.56 and 13.66±3.32, respectively). The mean (±SD) DFI score of parents of children with mild, moderate and severe AD was 9.62±2.76, 14.68±2.26 and 18.13±1.97, respectively.

The DFI score of parents of children with severe AD was significantly higher ($P<0.001$) as compared to mild and moderate AD (Table 1). Sex of children and education level of parents had no effect on DFI score.

The mean score for each DFI domain is presented in Table 2. The highest scoring items were expenditure (mean score 1.74), sleep disturbance (mean score 1.73), food preparation (mean score 1.67) and emotional distress in parents (mean score 1.6). Tiredness and exhaustion in parents and housework were moderately affected, while the least affected areas were family leisure activity, treatment difficulties, time for shopping and relationship between family members.

DISCUSSION

Of all skin diseases affecting children, AD has one of the greatest impacts on the child's quality of life (17). The range of ways in which family lives are affected by AD is similar to the extent of the impact of other systemic diseases. The range of problems caused by child's AD may in turn affect the health of the child, either directly where

Table 2. Scores of each Dermatitis Family Impact (DFI) domain

DFI and its domains	DFI score (mean ± SD)
Total DFI	13.86±4.23
Housework	1.37±0.65
Food	1.67±0.74
Sleep	1.73±0.89
Family leisure activity	1.2±0.7
Time for shopping	1.1±0.83
Expenditure	1.74±0.77
Tiredness	1.4±0.66
Emotional distress	1.6±0.61
Relationships	0.9±0.65
Treatment	1.15±0.63

SD = standard deviation

financial limitations restrict access to treatment, or indirectly where the problems cause stress with further adverse effects on the skin condition. This may in turn affect the social and psychological development not only of the child but also of other family members (10). Many tools have been used to assess the quality of life of children with AD and their parents or caregivers. The DFI questionnaire is a useful tool that comprehensively determines the effects of the child's AD on the lives of parents (10).

In our study, the mean DFI score of parents of AD children was 13.86, which is higher as compared to the mean DFI scores recorded by Ricci *et al*. (mean DFI score 11) (5), Lawson *et al*. (mean DFI score 9.6) (10) and Beattie *et al*. (mean DFI score 8.47) (11). In our study, 30% of children had severe AD. This may be the reason for the higher mean DFI score in our study. Also, we found a statistically significant (P<0.001) difference in the mean DFI score between the parents of children with a positive and negative family history of atopy. This aspect has not been seen in other similar studies (5,10,11). Social class of parents of atopic children had a significant effect on the mean DFI score in our study, whereas in the study performed by Ben-Gashir *et al*. (12) social class had no effect on DFI score.

In the present study, the parents of children with severe AD had a statistically significantly (P<0.001) higher mean DFI score as compared to parents of children with mild and moderate AD. This finding is in accordance with previous reports (5,11,12), suggesting that the increase in the severity of AD has a negative impact on the quality of life of parents of these children. This in turn has negative impact on the child's health, as parents are primary caregivers to their children. Our finding also supports the construct validity of the DFI and is in agreement with the finding of Lawson *et al*. (10) that the severity of the child's AD and the severity of family life disturbance are related (r=0.55; P=0.002). In our study, the age of children with AD had no impact on the quality of life of their parents (Table 1).

The analysis of DFI domains in our study revealed the greatest impact on the domains assessing expenditure for the management of the child's AD and disturbed sleep of family members. This correlates with previous reports (5,18). Disturbance in food preparation was found to be among the three highest scoring items in our study, while this aspect of DFI domain was found to be among the lowest scoring items in other studies (12,18). This difference may be due to different customs of food preparation between our country and the countries where these studies were performed. In our study, emotional distress in parents was found to be among the highest scoring items of DFI domains, which is in accordance with previous studies (10,11). The domains of tiredness and exhaustion in parents and housework were moderately affected in our study, similar to a previous study (10). Family leisure activity, treatment difficulties, time spent in shopping and relationships between family members were the least scoring items of DFI in our study, corresponding to the results reported by Beattie *et al*. (11), but the domain of treatment difficulties scored highest in the study performed by Lawson *et al*. (10).

CONCLUSION

The severity of the child's AD directly affects the quality of life of his/her parents. The findings of our study help us get better knowledge of practical difficulties faced by parents of children with AD and will help us improve the treatment strategy for atopic children. The DFI is of value to guide appropriate management of children with AD and can be used as an added parameter in clinical trials concerning the management of children with AD.

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