

The Impact of Childhood Atopic Dermatitis on the Patients' Family

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Abstract: Atopic dermatitis is a common childhood disease that impairs quality of life. The study aimed to clarify the impact of childhood atopic dermatitis on family life and to correlate severity of atopic dermatitis with family life. A cross-sectional survey was conducted at Qassim Region of Saudi Arabia over a period of 4 months extending from April to July 2009. The parents of children with atopic dermatitis were asked through a validated "Dermatitis Family Impact Questionnaire" about the impact of the disease on their life. For each questionnaire, a total score of 0 to 5 is considered as normal quality of life, 6 to 10 as low, 11 to 20 as moderate and >20 as high alteration in quality of life. The severity of the disease was evaluated using the SCORAD index. A total of 447 children with atopic dermatitis were included in the study. Their mean age was 65.9 months. Males constituted 57% of the patients. The mean score for quality of life in affected families was 13.9 (minimum 2, maximum 25). Based on our suggested classification, only 15 (3.4%) had normal quality of life, 104 (23.3%) were mildly affected, 297 (66.4%) were moderately affected, while 31 (6.9%) reported severe alternation in their quality of life. Sleep, monthly expenditure, and food preparation were the activities showing the highest level of disturbance. The disturbance in quality of life was significantly correlated to increasing severity of the disease. The study has emphasized the importance of investigating the quality of life of atopic dermatitis families. A simple questionnaire is a useful guide for appropriate management of the disease.

Atopic dermatitis (AD) is a common, chronic inflammatory and recurrent skin disease that is characterized mainly by pruritus and skin dryness. It has shown a marked increase in prevalence in recent years. It affects up to 20% of the infant population in most communities and results in significant impact on the quality of life of

children and their parents (1–3). A hospital based study from Saudi Arabia has shown that atopic dermatitis constituted 35% of all eczema/dermatitis patients (4). It also accounts for 10% to 20% of referrals to secondary care dermatology clinics and often requires several visits, consuming valuable time and resources (5). The disease

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may have an acute onset especially in severe cases, and symptoms vary from individual to individual. While the condition remains mild in most cases, a tendency is shown to remit and exacerbate unexpectedly. This chronically relapsing course not only affects the child and his development but also disrupts the quality of life of the entire family (6–10). Given the potential impact of this common childhood disease, the quality of life of children and their families is clearly a crucial outcome in the disease management.

Although the effect of atopic dermatitis on child's quality of life is well documented (11,12), little information concerning its effects on different aspects of family life and function is available. The aim of this study was to clarify the impact of childhood atopic dermatitis on family life and to correlate it with disease severity.

METHODOLOGY

Setting and Population

This study is a cross-sectional survey conducted at Qassim Region of Saudi Arabia over a period of 4 months extending from April to July 2009. Selected general and specialist hospitals in the area were invited to participate in this study. The parents of all children aged 6 months to 12 years with diagnosis of atopic dermatitis fulfilling the criteria of Williams et al (13) and attending the dermatology clinics of participating hospitals were invited to participate in this study. Families were excluded if the child or siblings were suffering from any significant medical or dermatologic condition that might have affected family's quality of life because such conditions might interfere with estimation of family impact of atopic dermatitis.

Preliminary orientation meetings were conducted with physicians working at pediatric clinics of the participating hospitals to discuss the purpose of the study. They were educated about the diagnostic criteria of atopic dermatitis, grading of disease severity and methods of data collection from the families of AD children.

Approval for conducting this study was obtained from the research and ethical committee of Qassim Medical College.

The Questionnaire

The Dermatitis Family Impact Questionnaire used in this study was based on a validated short version of a more detailed questionnaire designed by Lawson et al (1) It consisted of only 10 questions that encompass all topic areas covered by the original detailed version. This questionnaire is designed to ask respondents to evaluate

the impact of atopic dermatitis on particular areas of family function and includes questions regarding the influence on household work, meal preparation, sleep, leisure time and entertainment, shopping time, expenses, fatigue and tiredness, mood and emotional stress, relationship between family members, and general life.

The Arabic version of the questionnaire was tested for understandability and feasibility. Each question was assigned a score from 0 to 3 with a maximum possible score of 30. The zero score indicated no influence and score 3 indicated the highest impairment of the function. For study analysis, we considered a total score of 0 to 5 as normal, 6 to 10 as low, 11 to 20 as moderate, and > 20 as high alteration in quality of life. This classification used by the author is based on a previously published classification to obtain a more informative parameter (14).

Assessment of Disease Severity

The severity of AD was evaluated using SCORAD index (SCORing Atopic Dermatitis) (15). The patients were classified into the following three categories: mild disease (SCORAD < 20), moderate disease (SCORAD 20–40), and severe disease (SCORAD > 40). Clinical examination and evaluation of the disease severity were made by the same physician who interviewed the family for their quality of life.

Data Collection and Analysis

The sample size was estimated to detect an attitude of parents regarding impact of their AD children on the family conditions using a prevalence rate 25% with confidence level of 95%, a power of 80%, and a precision of 4%. The estimated sample size was 430 patients.

The questionnaire was filled by the attending physician during the clinical encounter with parents of children with atopic dermatitis. Data analysis were made by using the Statistical Package for Social Sciences (SPSS 17.0). Frequency distributions of all variables were calculated. All *p* values were based on 2-sided tests, and the cut-off value for statistical significance was set at 0.05. Chi-square analysis was used to test differences in proportions and independent Student's *t* test was used for analysis of quantitative data.

RESULTS

Of 480 parents invited for the study, 447 answered the questionnaire giving a response rate of 93.1%. Table 1 shows the social and demographic characteristics of children and their parents. The ages of children ranged

TABLE 1. Social and Demographic Characteristics of Patients and Their Families

Characteristics	(n = 447)
Age in months (mean $\pm$ SD)	65.9 $\pm$ 32.9
Child's gender	
Male	255 (57%)
Female	192 (43%)
Parent's education	
Secondary	179 (40.0%)
High	268 (60.0%)
Social class	
Low	60 (13.4%)
Intermediate	284 (63.5%)
High	103 (23.0%)
Family history of allergies	
Yes	77 (17.2%)

from 17 to 130 months with an average of 65.9 months. Fifty seven percent of children were male. High proportion of parents (60%) had received higher education. Most patients (63.5%) belonged to intermediate social class. History of allergies in the family was reported by 17.2% of respondents. The main allergic problems were bronchial asthma (58.4%) and allergic rhinitis (41.6%).

The mean score for quality of life in affected families was 13.9 (minimum 2, maximum 25). Only 15 (3.4%) had normal quality of life, 104 (23.3%) were mildly affected, 297 (66.4%) were moderately affected, while 31 (6.9%) reported severe alternation in their quality of life.

Figure 1 shows the level of alteration in various functions and activities of the families caused by the disease of their children. The sleeping time, monthly expenditures, and meal preparation were affected to the highest level. Other family activities and functions

showing various levels of alterations included daily activities, leisure time, shopping, feeling of tiredness, psycho-emotional aspects, relations with other family members and effect on general life. Only a small proportion of families reported that most of their activities are normal despite the diseased child in the family. Preparation of meals and psycho-emotional stability, however, were affected in all the cases.

Table 2 depicts the relation between quality of life and the demographic characteristics of children and their families. Clearly, the quality of life of families of female patients is more severely affected than that of male patients ($p < 0.01$). The quality of life showed a significant association with family's educational level. The families with secondary education were more severely affected than families with higher education ($p < 0.01$). Similarly, the intermediate social class was found to have a significantly high association with disturbance of quality of life, while families belonging to low or high social classes were less affected.

Figure 2 shows the correlation between severity of the disease as evaluated by the attending physicians—as measured by the SCORAD index—and the Dermatitis Family Impact score. It is evident that a clear strong positive correlation ($r = 0.79$) is found, where quality of life is severely disturbed by increasing severity of the disease.

DISCUSSION

The results of this study documented that presence of a child with AD can greatly affect the quality of life of other family members. Based on our suggested classification,

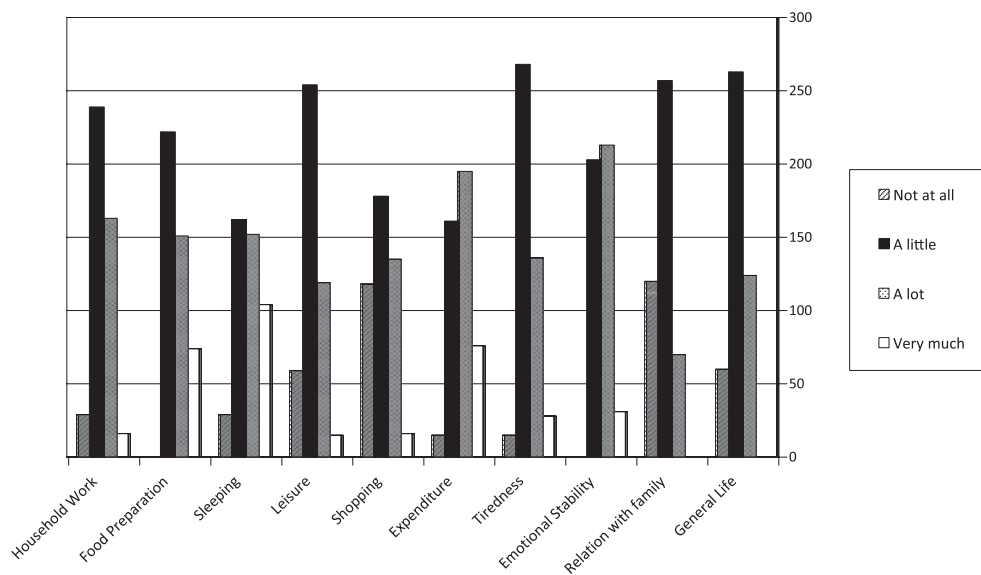
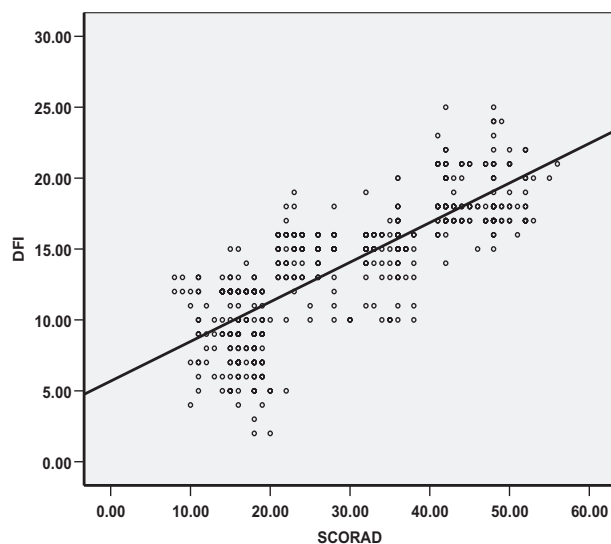


Figure 1. Reported disturbance in functions and activities of families caused by disease of their children.

TABLE 2. *Relation Between Quality-of-life Categories and Demographic Characteristics*

Characteristics	Quality of life				Total	p
	Normal	Mild	Moderate	Severe		
Gender						
Male	15 (5.9%)	61 (23.9%)	179 (70.2%)	0 (0%)	255	< 0.01
Female	0 (0%)	43 (22.4%)	118 (61.5%)	31 (16.1%)	192	
Education						
Secondary	15 (8.4%)	44 (24.6%)	104 (58.1%)	16 (8.9%)	179	< 0.01
Higher	0 (0%)	60 (22.4%)	193 (72.0%)	15 (5.6%)	268	
Social CLASS						
Low	0 (0%)	0 (0%)	60 (100%)	0 (0%)	60	< 0.01
Intermediate	15 (5.3%)	89 (31.3%)	149 (52.5%)	31 (10.9%)	284	
High	0 (0%)	15 (14.6%)	88 (85.4%)	0 (0%)	103	

**Figure 2.** Correlation of DFI (Dermatitis Family Impact) score with severity of atopic dermatitis.

the quality of life was moderately affected in 66.4% and severely affected in 6.9% of our cases. Some previous studies have revealed that families of children with AD often report lower quality of life than families of healthy children (1,16). This is hardly surprising because AD commonly affects children and the parents have to share extra burden of caring for a diseased child. This can greatly impact family dynamics as well as family life in general. An Australian study reported that taking care of a child with moderate or severe AD was more stressful than caring for a child with insulin-dependent diabetes (17).

A recent qualitative investigation into the family impact of childhood AD suggested several areas where AD impacts the family. These areas were similar to those investigated in our study and included sleep issues, lifestyle changes, social impact, family activities, financial stresses, and personal strain (14). Sleep deprivation, financial burden, and meal preparation were the major

activities showing the greatest impact caused by the presence of AD child in the family in our study. Some previously published studies have reported that the major stress-causing factor, which most families deal with, is sleeplessness as a result of itching in a child with AD (16–18). Sleep deprivation can affect all family members including siblings. Long et al (18) found that 60% of a sample of parents of children with AD rated loss of sleep as a significant problem. Other researchers have noted that parents can lose up to 1 to 2 hours of sleep per night while dealing with AD symptoms. Such loss of sleep can translate into poor work performance and decreased coping skills both at work and at home (19). Additional factors that add to the burden of caring for a child with AD are the financial costs of treatment, time missed from work for physician appointments, and lack of understanding and social support from friends and family members (20,21). Other studies have presented similar data, and several investigators are beginning to build conceptual models of family impact based upon these data (1,21,22).

Many AD families are advised to make lifestyle changes, including restricting or modifying diets; using special soaps and detergents; wearing clothing or using linens of all natural fibers; adding dust mite protectors; and removing carpets (22). These lifestyle changes take time to implement and are often a strain to the family's budget. In addition, treatment for AD can be a very time-consuming process for the parents or caregivers, and affects the amount of time they have for other family members and for themselves. Estimates by Su et al (17) suggested that 2 to 3 hours per day are spent caring for a child with AD. Mothers of children with AD are more likely to show their affection in terms of a hygienic ritual, which in turn changes the relationship dynamics between the mother and the child to more of a nurse-child relationship (23). In addition, the burden of caring for the child with AD can negatively affect spousal relationships

and interfere with giving adequate attention to siblings (16).

The results of this study indicated that quality of life was significantly more disturbed with increasing severity of the disease. 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 (24). However, coping ability of a family to an existing disease is a complex subject where many inter-related factors come into play. Some families with severe disease may cope very well and show low disruption in their life quality.

Food allergy has a pathologic role in many children with atopic dermatitis. However, determination of the role of food allergy in patients with atopic dermatitis is more difficult and may require additional diagnostic maneuvers, including elimination diets and oral food challenges. The coexisting food allergy in AD children can further impair the quality of life of the family because of additional testing and need to eliminate offending dietary elements. To investigate this impact, a Health-Related Quality of Life "HRQL" questionnaire, or a Child Health Questionnaire (CHQ-PF50) is needed. A study performed in U.S. showed that lowest scores of life quality were found among those with food allergy in conjunction with atopic dermatitis and asthma particularly in the area of general health, but the study did not demonstrate much impact in areas of physical functioning, emotional/behavioral problems, or self-esteem and actually found higher scores in the area of family cohesion (25).

Results obtained from our questionnaire analysis have shown some peculiarities of the Saudi community in responding to the disease in a family member. First, relationships with other family members were minimally disturbed in our study group, indicating that family ties and attachments in the Saudi community are strong and more resistant to violation by disease or discomfort. Second, the quality of life of families with female AD children was significantly more affected compared with families of affected male children. In traditional communities like Saudi Arabia, female children are more dependant and vulnerable member of the family. It is highly expected that disease in female child generates more anxiety and concern among the parents because of perceived problems in marriage proposals and post-marriage relationships.

The effects of AD on the family can be extensive and pervasive, but as AD is not life threatening, families often do not receive potentially useful educational or psychosocial support, which can result in further stress and frustration. Results of this study have highlighted the

importance of investigating the quality of life of AD families. Because atopic dermatitis can have a significant psychosocial impact on the family of the patients, it is clear that AD children and their families need more than just the physical treatment of symptoms. Parents of children with AD often need an appropriate management plan including an educational program and a carefully planned multidisciplinary approach for optimal care of the patients, with the participation of a pediatrician, a dermatologist, and a psychologist (26). In addition, specialist care for AD children may also be useful in decreasing the family impact of the condition. An episode of specialist care by the dermatologist is shown to be associated with decreased family impact of AD (21). A recent study examined the impact of an initial consultation with dermatology team on AD severity and quality of life impairment from the parent's perspective. It demonstrated the usefulness of these measures in routine clinical management of AD and showed the beneficial effect, for both infants and parents, of the initial consultation by a dermatology team in a secondary care setting (27). Further studies to develop educational programs for parents of children with AD to decrease the burden of the disease are necessary and highly needed.

The questionnaire is a useful tool for better understanding and evaluating the needs of families with AD children. The questionnaire analysis can provide useful information on different aspects of family life and helps to improve the clinical approach to the child and the family. Universal use of such questionnaire for managing families of AD children is recommended.

CONCLUSION

Results of this study have highlighted the importance of investigating the quality of life of AD families. A questionnaire analysis is useful to measure the impact of AD on family life and acts as a useful guide for appropriate management of the disease. The questionnaire used in our study is simple, short, and easy to administer. It does not include any sensitive questions and needs no special skills for application. We recommend its universal use for managing families of AD children. A multidisciplinary management approach can help to improve the quality of life of families with children affected by AD. This type of program may be as important as, and potentially more cost effective than, developing new medical treatment for the disease.

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