

## The Impact of Infantile Atopic Dermatitis on Patients' and their Families' Quality of Life

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### Abstract

#### Background

Atopic dermatitis (AD) is detrimental to the infants' and their families' quality of life. We aimed to study the disease effects on Iranian infants and their families applying the infants' dermatitis quality of life index (IDQOL), and the dermatitis family impact questionnaires (DFI).

#### Materials and Methods

Questionnaires (DFI and IDQOL) were translated into Persian and retranslated into English. Three experts assessed the content validity of the questionnaires by evaluating the relevance and transparency of the tools. Test-re-test was used to evaluate the questionnaires reliability. The reliability and internal consistency of the IDQOL and DFI were accessed by Cronbach's alpha coefficient which was 0.74. The construct validity of the questionnaires was assessed using the Pearson correlation index to evaluate convergent and divergent validity. 50 Infants with AD fulfilling the criteria as well as their parents entered the study in Mashhad, Iran, in 2017. An independent-sample t-test was used to compare mean scores and one-way ANOVA was used to analyze other data.

#### Results

Intense itching (64%), taking one to more than two hours to get the child to sleep (52%), and three to more than five hours of infant sleep disturbance (34%) were significant. Family expenses (70%), and emotional stress (68%) affected the families' quality of life prominently. There were significant differences between the average DFI scores and other allergic diseases, both among infants suffering from AD ( $p = 0.04$ ), and their families ( $p = 0.03$ ).

#### Conclusion

The Persian versions of the questionnaires (DFI and IDQOL) have validly and reliably measured both groups' quality of life. They experienced remarkable disturbances in their quality of life.

**Key Words:** Atopic, Dermatitis, Eczema, Infantile, Life quality, Skin diseases.

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## 1- INTRODUCTION

The atopic dermatitis (AD) is a chronic and recurrent inflammatory cutaneous disease that significantly impairs the quality of life of both the afflicted infants and their parents. The condition impacts the patients' families in terms of time and economic resources, imposing a considerable burden on society. Previous research has determined AD prevalence to be as high as 20% and appears to be rising annually (1). In addition to the various cutaneous and non-cutaneous complications, AD causes psychosocial suffering and misery to both children and their principal caregivers (2-4). The itching, bathing and sleeping difficulties, if addressed improperly, may lead to behavioral disorders in the affected child. The infant's irritability would negatively affect the parents' supportive care; moreover, deprivation of skin-to-skin contact due to the infant's dry, scaly skin might impact the parent-child relationship. The quality of life for children with chronic skin diseases such as AD is at least as impaired as that experienced by children with other chronic childhood diseases (5).

According to the World Health Organization (WHO), a child's health-dependent quality of life depends on multidimensional concepts of physical and psychosocial growth. This concept is widely used to evaluate children's physical and mental health and their general welfare. Promoting children's quality of life should be a priority for both governments and a modern society. The high prevalence of AD, its widespread complications for infants and their families, and the consequent economic effects have led to the development of valuable surveys like IDQOL and the dermatitis family impact questionnaires (DFI). We studied the AD effects on both infants and their families applying the Infants' Dermatitis Quality of Life Index (IDQOL), and DFI questionnaires.

Moreover, additional factors that might affect the quality of life of atopic infants and their parents should also be considered.

## 2- MATERIALS AND METHODS

### 2-1. Study design and population

This descriptive study was conducted on 50 infants under two years of age who were diagnosed with AD according to the modified Hanifin and Rajka criteria (6), in the pediatric dermatology or allergy clinics in Mashhad, Iran, in 2017.

### 2-2. Methods

The IDQOL, the DFI and a checklist (including baseline characteristics) were distributed to all parents who completed the informed consent form. The checklist surveyed the patient's age and gender; the parent's age and education; the father's career; the number of individuals living in the family home and where the patient fell in the age order of the other family members; the availability of medical insurance; issues obtaining transportation to the hospital, any additional allergic diseases of the patient, such as asthma, food allergy and hay fever; and the allergic or chronic diseases of other family members. The IDQOL has 11 questions. The first question ranks the dermatitis severity, while the other questions are related to quality of life indexes that are scored on a range of none to very much (**Tables 1 and 2**, respectively).

A maximum score of 30 reflects the greatest quality of life impairment. The DFI poses 10 questions and has a similar structure and scoring system with a maximum score of 30. The questions are illustrated in **Table.3**. The answers to both the IDQOL and the DFI questions should be based on the frequency of a specific behavior or emotion in patients as well as its consequences on family life for the entirety of the previous week.

## **2-3. Measuring tools**

### **2-3-1. Translation and review of content validity**

First, the IDQOL and DFI were translated into Persian by two separated translator groups. Gradually, the final Persian versions were prepared. These versions were translated by specialists in English so, they were compared with the original questionnaires and the final versions of the Persian ones were approved by the research team. A panel of three experts assessed the validity of the Persian and English translations. They were asked to evaluate the relevance, transparency and comprehensiveness of the tools.

### **2-3-2. Inter-rater agreement**

The degree of overall agreement index indicates the degree of agreement observed between the experts participating in the study on the indicators of the occasion and the transparency of the questionnaires.

### **2-3-3. Content validity index (CVI)**

In order to calculate the relevance of each question, the total number of specialists who have identified the suitability of each question appropriately were divided into the total number of specialists, then the domain index is a number between zero and one. The transparency index of each question was calculated in exactly the same way.

### **2-3-4. Reliability**

Test-re-test was used to evaluate the IDQOL and DFI reliability. To evaluate the validity and relevancy of the questions, 10 parents having infants with AD were asked twice to write their opinions about the clarity and simplicity of the questions with a two-week interval, which were then rechecked by the research team. The reliability and internal consistency of the IDQOL and DFI were assessed by Cronbach's alpha coefficient (Cronbach's alpha index was determined to be 0.74).

The Pearson correlation index was used to evaluate the construct validity of the questionnaires using two parts of convergent and divergent validity.

### **2-4. Inclusion and exclusion criteria**

Inclusion criteria were infants under two years of age who had been diagnosed with AD according to the modified Hanifin and Rajka criteria (6). The children whose parents were not willing to participate in the research project or were not reliable to share the information and children with other significant medical or dermatological conditions, were excluded from the study.

### **2-5. Data Analysis**

For statistical analysis, an independent-sample t-test was used to compare mean scores, and a one-way ANOVA test was used to analyze other data due to the normal distribution. This study assessed the validity and reliability of the infants' dermatitis quality of life index (IDQOL) and the dermatitis family impact questionnaire (DFI) on Iranian infants and their families. Our team also examined the impact of other potential factors that were not included in the questionnaires, including the caregivers' education and career and patient insurance. Data were analyzed using SPSS software version 16.0. P-value of  $< 0.05$  was considered statistically significant.

### **2-6. Ethics**

Parental Satisfaction was obtained for participation in the study. Writing a name was not required. Permission to develop a Persian version of the IDQOL and the DFI was granted from the University of Wales, College of Medicine, Cardiff, United Kingdom.

## **3- RESULTS**

This study surveyed 50 infants with AD and their families. The frequency and frequency percentage of the baseline characteristics, are illustrated in the

following tables (**Tables. 1, and 2**). Cronbach's alpha index was determined to be 0.74, representing an appropriate reliability. According to the first IDQOL question, dermatitis severity (being red, scaly, inflamed and widespread) was ranked by the number of surveyed patients as follows: extremely severe, 7 (14 %); severe, 26 (52 %); average, 13 (26 %); fairly good, 2 (4 %); and none, 2 (4 %). The frequency and frequency percentages of the IDQOL and the DFI results are shown in **Tables 1 and 2**, respectively. The mean scores of the IDQOL, and the DFI based on the baseline characteristics of the infants and their parents are included in **Table 3**. The three IDQOL factors having the most prominent effects were: intense itching (64%, n=32), taking one to more than two hours to get the child off to sleep (52%, n=26), and three to more than five hours of infant sleep disturbance (34%, n=17). The IDQOL

factors with the lowest scores were the disease impact on children's dressing or undressing and bathing, which were little or none in 90% (n=45), and 88% (n=44) of the respondents, respectively. Family expenses due to the infants' disease (70%, n=35), and the emotional stress experienced by other family members (68%, n=34) were the most significant factors affecting the families' quality of life. In the DFI questionnaire, differences in the responses to the questions regarding the child's other allergic diseases, and other family members' allergic conditions were statistically significant. The results of the correlation test demonstrated that there was no relationship between the average scores of both questionnaires, and the quantitative information like infants' and parents' age, the number of children in a family, and the patients' placement in the age order of their family members.

**Table-1:** Frequency and frequency percentage of quality of life among atopic infants.

Itching and Scratching	All the time	A lot	A little	None	-
	6(12%)	26(52%)	12(24%)	6(12%)	-
Child's mood	Always crying	Extremely difficult	Very fretful	Slightly fretful	Happy
	3(6%)	8(16%)	8(16%)	24(48%)	7(14%)
Time to get the child off to sleep, hour	More than 2	1-2	15 mins-1	0-15 mins	-
	11(22%)	15(30%)	17(34%)	7(14%)	-
The total time of sleep disturbance, hour	5 hrs or more	3-4 hrs	1-2 hrs	Less than 1hr	-
	3(6%)	14(28%)	10(20%)	23(46%)	-
Eczema interferes with playing or swimming	Very much	A lot	A little	Not at all	-
	2(4%)	7(14%)	16(32%)	25(50%)	-
Eczema interferes with taking part in or enjoying family activities	Very much	A lot	A little	Not at all	-
	2(4%)	9(18%)	20(40%)	19(38%)	-
Any problems with child's eczema at mealtimes	Very much	A lot	A little	Not at all	-
	2(4%)	7(14%)	17(34%)	24(48%)	-
Any problems with dressing or undressing	Very much	A lot	A little	Not at all	-
	2(4%)	3(6%)	24(48%)	21(42%)	-
Any problems at bath time	Very much	A lot	A little	Not at all	-
	1(2%)	5(10%)	28(56%)	16(32%)	-

**Table-2:** Frequency and frequency percentage quality of life in atopic infants' parents.

Effects of Child's Eczema on Family	Very	A lot	A little	Not at all
Child's eczema affects on housework	5(10%)	16(32%)	22(44%)	7(14%)
Child's eczema affects on food preparation and feeding	6(12%)	11(22%)	25(50%)	8(16%)
Child's eczema affects on the sleep of others	6(12%)	10(20%)	25(50%)	9(18%)
Child's eczema affects on family leisure activities	4(8%)	15(30%)	18(36%)	15(30%)
Child's eczema affects on time spent on shopping	2(4%)	15(30%)	18(36%)	15(30%)
Child's eczema affects on expenditure	15(30%)	20(40%)	11(22%)	4(8%)
Child's eczema affects on parent's emotional distress	10(20%)	24(48%)	12(24%)	4(8%)
Child's eczema affects on life	9(18%)	22(44%)	14(28%)	5(10%)

**Table-3:** Comparison of the score average of IDQOL and DFI questionnaires

Items that might affect both groups' quality of life	Subset	IDQOL	DFI
Gender	Female	32.8±4.5	20.2±5.2
	Male	33.2±5.7	20.2±5.5
	P- value	0.07	0.3
Mother's Education	Under-graduate	32.9±5.7	19.6±5.3
	Post-graduate	33.1±5.2	20.5±5.4
	High school diploma	34±0	24±0
	P- value	0.7	0.9
Father's Education	Under-graduate	33.1±6	20.4±6.1
	Post-graduate	33.2±5.2	20.3±5.1
	High school diploma	30.5±4.9	19±7
	P- value	0.9	0.7
Father's career	Unemployed	29±2.8	18.5±2.1
	Employee	34.6±5.5	20.5±5.9
	Private	32.6±5.3	20.2±5.3
	P- value	0.9	0.7
Having Insurance	Yes	33.1±5.2	20.2±5.4
	No	31.7±7.4	20.7±4.3
	P-value	0.6	0.8
Transport Problems	Yes	33.6±4.1	20.4±5.5
	No	32.7±6	20.1±5.3
	P- value	0.5	0.8
Child's other allergic disease	Yes	32.6±5.7	33.3±5.1
	No	18.3±6.2	21.4±4.4
	P- value	0.4	0.04
Atopic dermatitis in other members of family	Yes	33.3±6.6	33.1±4.3
	No	20.4±5.5	20.2±5.4
	P- value	0.9	0.9
Allergic diseases in other members of family	Yes	32.2±5.1	34±5.6
	No	18.7±5	22±5.3
	P- value	0.2	0.03
Any chronic disease in other members of child's family	Yes	31.8±6.2	19.8±3.6
	No	33.2±5.3	20.3±5.5
	P- value	0.5	0.8

DFI: dermatitis family impact; IDQOL: infants' dermatitis quality of life index.

#### 4- DISCUSSION

The purpose of the work was to study atopic dermatitis effects on both Iranian infants and their families applying the IDQOL and DFI questionnaires. Concurrent measurement of the quality of life for children and their involved families would be more accurate, because it would allow researchers to anticipate more reliable and precise responses. The three most prominent IDQOL factors were intense itching (64%), taking one to more than two hours to get the child to sleep (52%), and three to more than five hours of sleep disturbance (34%) in our study. Appropriate management of pruritus is still the most troublesome issue for AD patients. The resulting sleep problems have been the subject of studies conducted throughout the world, with reported adverse effects ranging from emotional, neurobehavioral and cognitive disorders to metabolic diseases like obesity (7-9).

Our research highlights the importance of discovering effective ways to ameliorate patient itching and to improve the quality of atopic infants' sleep. The IDQOL factors with the lowest scores were the disease impact on children's dressing or undressing and bathing, which were little or none in 90% and 88% of the respondents, respectively. In a survey using IDQOL and DFI, the factors of itching, the hours spent to get the child to sleep, and the patient's mood were ranked as having the most negative impacts on quality of life, while changing of the children's clothes had the least effect (10). These results are comparable to those of our study. Another study on 203 AD infants reported similar results to our research regarding the children's pruritus and the related sleeping problems; in contrast to our results, the third most troublesome factor in the Beattie study was bathing problems (11). A study by Alvarenga and Caldeira conducted in Brazil reported that the most prominent

factors affecting AD patients were itching, the infants' mood and treatment-related problems (12). Our study identified treatment cost (70%), and the emotional stress experienced by family members (68%) as factors that considerably impaired the family members' quality of life. According to Carroll et al., the negative effects on family members of AD patients were due to the long course of treatment, the patients' special diet, and the AD-related expenditures, the last of which was similar to the results of our survey (13). Psychosocial problems related to skin conditions are not unique to AD patients. Vitiligo and acne patients both suffer from similar social stigmatism. However, psoriatic and AD patients experience both physical and psychosocial complications that if properly addressed and treated can improve the patients' quality of life (5). However, social functioning scores are more disappointing for patients with atopic dermatitis than other chronic skin and systemic diseases (14). Monti et al., found that the psychological impacts of pediatric AD on family members could be even greater than that on patients (15). A statistically significant and mutual correlation was observed between the severity of pediatric AD and the negative impacts on the patient's family (15-17). Therefore, health service managers and, on a larger scale, social media and governments should support atopic children's families both socially and emotionally. Studies in other parts of the world have proven the validity and reliability of the IDQOL and the DFI (10, 15, 18). In order to achieve reliable results, cultural adaption of these quality of life questionnaires should be conducted by associated experts, as was done in this study.

##### 4-1. Limitations of the study

Small sample size was the limitation. Therefore, conducting the study using a

larger sample size would reflect better results.

## 5- CONCLUSION

In conclusion, our research demonstrates that the Persian versions of the IDQOL and DFI questioners have validly and reliably measured the quality of life in Iranian AD infants and their families. While pruritus and sleep disturbance significantly affected AD patients, pecuniary and emotional issues were the most important item for their families.

**6- CONFLICT OF INTEREST:** None.

## 7- ACKNOWLEDGMENT

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