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Family quality of life among families of children with atopic dermatitis

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Background: Atopic dermatitis (AD) may cause emotional distress and impairs the quality of life (QoL) in children and their families. **Objective:** We examined family QoL of children with AD and explored associated factors such as disease severity and psychosocial factors among parents of children with AD.

Methods: Study participants were 78 children (1 month to 16 years old) diagnosed with AD and their parents visiting an outpatient clinic of the Department of Pediatrics in Inha University Hospital. Data were collected using structured questionnaires and medical record review. Parents completed the Dermatitis Family Impact questionnaire (DFI), the Positive Affect and Negative Affect Schedule, the Satisfaction with Life Scale, and the Korean Parenting Stress Index. For children aged below 6-year-old, parents were asked to complete the Infants' Dermatologic Quality of Life. SCOring Atopic Dermatitis (SCORAD), Children's Dermatology Life Quality Index, and the Pediatric Quality of Life Inventory version 4.0 Generic Core Scale were also completed.

Results: The mean age of parents and children were 37.4 ± 5.3 years and 65.1 ± 45.7 months, respectively. Among them, 87.2% of parents were mothers and 60.3% of children were boys. The mean score of DFI was 11.2 ± 6.0 . The mean SCORAD score was 28.3 ± 16.1 . Family who experienced strong negative emotionality had a 3.8 times higher probability of experiencing a lower QoL than parents who did not (odds ratio [OR], 3.82; p = 0.041). Family of children with higher severity of AD had a 6.6 times (OR, 6.55; p = 0.018) higher probability of experiencing a lower QoL than their less-severe counterparts. Families of girls with AD had a lower QoL (OR, 8.40; p = 0.003) than families of boys.

Conclusion: Family QoL among parents of children with AD was low and associated with parent's psychosocial characteristics as well as disease severity of the children. Considering parental involvement in AD management for children, emotional support for parents can be helpful in long journey of disease management.

Key words: Dermatitis, aopic; Quality of life; Stress, psychological

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INTRODUCTION

Atopic dermatitis (AD) is a chronic, relapsing eczema that occurs commonly in children. AD is associated with not only genetic factors but also environmental factors such as pollutants, and food. The prevalence of AD in South Korea is gradually increasing due to a westernized social environment [1, 2]. The prevalence of AD in 2010 was 17.9% among Korean elementary school students and 11.2% among Korean junior high school students, showed a growing trend compared to a study done in 2000 [3]. AD also may increase anxiety, stress, and depression as well as discomforts due to skin symptoms, which all might lower children's quality of life (QoL) [4, 5]. In a study comparing QoL in children with chronic diseases, children with AD presented lower QoL than children with diabetes [6]. Family having children with AD are also vulnerable to have variety of physical and psychological difficulties. For example, parents often experience extreme fatigue, stress, frustration, and low QoL, particularly when their children showed slow or no improvement in their conditions [7].

Although previous studies investigated the impact of AD on children and their family [8-10], little is known in dynamics among various factors associated with QoL in children and their family, particularly severity of disease and psychosocial aspects of parents such as life satisfaction and parenting stress. Therefore, this study aimed to examine the family QoL and associated factors of children with AD and parents, particularly focused on disease severity and psychosocial factors of parents.

MATERIALS AND METHODS

Participants and study protocol

The study participants comprised 78 children who were younger than 18 years old and diagnosed with AD by a physician in accordance with Hanifin and Rajka's diagnostic criteria [11] and their parents. They were all recruited from December 1, 2014 to December 31, 2015 in Inha University Hospital located in Incheon, South Korea.

Data were collected using structured questionnaires and physical examination to assess severity of AD. We asked parents to complete questionnaires and children if they were older than 6 years old. We also collected demographic data of children and parents including age, gender, and the duration of diagnosed AD. All data collection for this study was conducted after approval of the Institutional Review Board of the Inha University (141031-3A).

Measurements

AD severity was measured using the SCORing of Atopic Dermatitis (SCORAD) Index. The SCORAD index was calculated by scoring the lesion area using the "rule of nine" and rating the intensity as 0–3 points for each item. Participants' symptoms were also assessed by summing up the degrees of pruritus and sleep disturbances that children and their parents felt. For the skin surface area involved, the researchers scored the following from 0 to 3 points: erythema, edema, oozing, crusts, lichenification, and skin dryness. The total score was calculated by using the following equation: area of lesion (0-100)/5 + objective symptoms (0-18) / 5 + subjective symptoms (0-20). The total score ranged between 0–103 points and AD was classified into mild (0-24), moderate (25–50), or severe (51–103) [12].

Parent-report questionnaire measurement

Parent-report questionnaires included family QoL, positive and negative effect, life satisfaction, and parenting stress. A descriptive summary is presented in Table 1. Family QoL was assessed using the Dermatitis Family Impact (DFI) scale. The DFI was originally developed to evaluate QoL of family by Lawson et al. [13] and was translated and validated by Cho et al. [14]. This instrument contained 10 items assessing the effects of children's AD on housework, meal preparation, leisure activities, shopping, medical expenditures, mental and physical fatigue, and family relations within the last week. Higher scores indicate greater effects. Total score is rated from 0 to 30 points, and a higher score indicates a poorer QoL.

The positive and negative emotionality of parents was evaluated using a Korean version of the Positive Affect and Negative Affect Schedule (PANAS) scale that was developed by Watson et al. [15], which was translated and adapted by Lee et al. [16]. The PANAS is a 20-item questionnaire assessing both positive and negative mood, which consists of 9 positive-affect items and 11 negative-affect items. In this questionnaire, the participants rated each item on a 5-point Likert scale according to the degree of agreement. Scores ranged from 0–36 for positive-affect items and 0–44 for negative-affect items.

Parents' life satisfaction was assessed using a Korean translation of the Satisfaction with Life Scale (SWLS) that was developed by Diener and colleagues [17, 18]. Parents were asked to provide

Variable	No. of items	Possible range	$Mean \pm SD$	Median (range)	Cronbach α
Parents					
DFI	10	0–30	11.2 ± 6.0	10.0 (1–25)	0.900
PANAS positive	9	0–36	15.0 ± 6.9	16.0 (0–32)	0.878
PANAS negative	11	0-44	9.8 ± 8.1	7.0 (0–36)	0.911
SWLS	5	5-35	22.8 ± 6.4	24.0 (9–32)	0.907
K-PSI, total	36	0-100	42.5 ± 30.6	40.0 (1–97)	0.898
PD			42.0 ± 30.6	40.0 (1–97)	
PCDI			35.1 ± 27.4	30.0 (1–99)	
DC			47.3 ± 31.0	50.0 (1–99)	
Children					
PedsQL 4.0	23	0-100	89.3 ± 9.5	92.9 (65.2–100)	0.796
CDLQI	10	0–30	4.8 ± 3.6	4.5 (0–14)	0.694
IDQoL	10	0–30	7.4 ± 5.2	6.0 (1–23)	0.847
SCORAD					0.791
Objective	6	0–18	21.4 ± 14.5	17.8 (1.4–68.9)	
Subjective	2	0–20	7.1 ± 5.4	6.0 (0–20)	
Total	8	0–103	28.3 ± 16.1	24.7 (6.7–79.9)	

Table 1. Descriptive statistics and reliability of study measurements (n=78)

SD, standard deviation; DFI, dermatitis family impact questionnaire; PANAS, positive affect and negative affect schedule; SWLS, satisfaction with life scale; K-PSI, Korean parenting stress index; PD, parental distress; PCDI, parent-child dysfunctional interaction; DC, difficult child; PedsQL 4.0, pediatric quality of life inventory version 4.0 generic core scale; CDLQI, children's dermatology life quality index; IDQoL, infants' dermatologic quality of life; SCORAD, SCOring of Atopic Dermatitis.

answers to 5 items on a 7-point Likert scale according to their degree of agreement. Scores ranged from 5–35 points [19].

The Parenting Stress Index-Short Form (PSI-SF) Abidin [20] is a 36-item measure of global parenting stress. Total scores >90 indicate clinically significant levels of stress. The PSI-SF consists of 36 items using a five-point response scale and three subscales: parental distress, parent-child dysfunctional interaction and child difficulty. We used a standardized Korean version of the PSI-SF, which has demonstrated high validity and reliability [21]. Each item is rated on a 5-point Likert scale and higher scores indicate experiencing higher levels of stress.

Generic QoL of children who were younger than 7 years old was measured by parents' proxy using a Korean translation of the Pediatric Quality of Life Inventory version 4.0 Generic Core Scale (PedsQL 4.0), which was developed by Varni et al. [22] and translated by the researchers. The PedsQL 4.0 consists of 4 areas: physical, emotional, social, and school, and was answered by children based on their experience or parents' proxy over the past month. The PedsQL 4.0 consists of 23 items scored on a 0- to

4-point Likert scale. Scores for each item were inversely converted and changed into a 100-point scale [23].

The dermatology specific QoL of infants was assessed by parent's proxy. We used the Infants' Dermatologic Quality of Life Index, which was developed by Lewis-Jones and Finlay [24] and translated in Korean by Cho et al. [14]. It consisted of 10 items including items asking about children's eating habits, and difficulties over the course of treatment. The total score ranged from 0–30 points and higher scores indicated a worse QoL.

Children's self-reported questionnaire measurement

Generic QoL of children who were older than 7 years old was assessed by self-report using a Korean translation of the Pediatric Quality of Life Inventory version 4.0 Generic Core Scale (PedsQL 4.0) [22]. Dermatologic specific QoL of children who were older than 6 years old was assessed by self-report using Children's Dermatology Life Quality Index (CDLQI). The CDLQI was developed by Lewis-Jones and Finlay [25] and translated by Bang [26]. This questionnaire comprised 10 questions about AD symptoms, friendship, daily life, hobbies, school life, and sleep. Scores ranged from 0–30 points and higher scores indicated poorer QoL.

Statistical analysis

Collected data were statistically analyzed using IBM SPSS Statistics ver. 21.0 (IBM Co., Armonk, NY, USA). We tested the normality of study variables using histograms and the Shapiro-Wilk test and found that family QoL, life satisfaction, PANAS negative affect, and parenting stress were not normally distributed. To assess bivariate associations among variables with a normal distribution, we used Pearson correlation for correlational analysis and *t*-tests for mean comparisons. For variables without a normal distribution, we used Spearman correlation for correlational analysis and the Mann-Whitney *U*-test for mean comparisons.

We used a logistic regression analysis to estimate family QoL. We selected variables to build our logistic regression model based on the bivariate analysis. We coded as 1 if the severity of AD was 25 or higher [27] and the K-PSI was 85 or higher [20]. We used means of other variables for cutoffs. We coded as 1 if DFI \geq 11, SWLS \geq 23, PANAS-positive \geq 15, PANAS-negative \geq 10, PedsQL \geq 89, CDLQI \geq 6, and IDQOL \geq 6. To present the results of the logistic regression analysis, we provided odds ratio (OR), 95% confidence intervals (CIs) and p-values. All statistical analyses were performed based on a two-tailed test and an alpha level = 0.05.

RESULTS

There were 156 participants (78 children with AD and 78 parents). The mean age of parents was 37.4 ± 5.3 years and the majority of parents (87.2%) were mothers. Of the 78 children, 31 were girls (39.7%) and 47 were boys (60.3%). The mean age of children with AD was 65.1 \pm 45.7 months and the mean duration of AD was 21.0 \pm 33.2 months.

The results of the descriptive statistical analysis for each variable are shown in Table 1. Table 2 shows the correlations between family QoL and parents' characteristics. Family QoL showed statistically significant correlations with parents' negative affect and parenting stress. Life satisfaction was correlated with both positive and negative affect. Parenting stress was negatively correlated with life satisfaction and positive effect and positively

correlated with negative effect. All these correlations were statistically significant (p < 0.001).

Table 3 shows the correlations between family QoL and children's characteristics. Family QoL was statistically significantly correlated with both generic QoL and dermatology QoL, SCORAD scores, and gender. Parents' life satisfaction was correlated with generic QoL and dermatology QoL of children. Although parents' positive affect showed no statistically significant correlation with children's characteristics, parents' negative affect was correlated with dermatology QoL of children. Parenting stress was correlated with both generic QoL and dermatology QoL of children. Parenting stress was correlated with both generic QoL and dermatology QoL of children.

Table 4 shows the results of the logistic regression analysis to predict DFI. An overall test of model coefficients for the adequacy of model verified that this model was significant compared with a null model that included a constant term only. This model was also estimated to be appropriate to predict dependent variables and was confirmed to have an explanation power of 49.3%. The logistic regression analysis revealed that parents' negative affect, children's gender, and AD severity were statistically significant independent contributors of family QoL. In other words, parents who experienced a strong negative emotionality had a 3.8 times higher probability of experiencing low QoL than those who did not. In addition, parents of girls with AD had an 8 times higher probability of experiencing low QoL than parents of boys with AD were. Parents having children with a high AD severity had a 6.6 times higher probability of experiencing low QoL than parents of children with less severe AD.

DISCUSSION

This study was conducted to understand the QoL in children with AD and their parents focusing on the psychological factors of parents, and the QoL and AD severity of children. We found that family QoL among family of children with AD was similar or lower than those of previous studies [14, 28]. Shin and their colleagues reported that family QoL using the same DFI questionnaire was 11.0 \pm 6.8 points on average [28], which was similar to our result. However, when median values of DFI were compared between two studies, our study result was much lower than the median value of 23.0 (interquartile range [IQR], 17.0–28.0) presented in the previous one [14]. Such a difference is thought to be due to differences of age and AD severity of study participants. For example, children in our study were much

able 2. Conclution between naming cole (bir) and psychological factors (5wes, 174445, and 1715) and characteristics of parents					
Variable	DFI [*]	SWLS [*]	PANAS positive	PANAS negative [*]	K-PSI [*]
DFI [*]	-	-0.213 (0.062)	-0.211 (0.063)	0.483 (<0.001)	0.550 (<0.001)
SWLS*	-	-	0.555 (<0.001)	-0.309 (0.006)	-0.491 (<0.001)
PANAS positive	-	-	-	-0.098 (0.393)	-0.414 (<0.001)
PANAS negative	-	-	-	-	0.483 (<0.001)
Gender [‡]	-0.629 (0.529)	0.315 (0.753)	-0.550 (0.584) [†]	0.187 (0.851)	-0.037 (0.970)
Age	-0.147 (0.198)	-0.175 (0.126)	-0.185 (0.104)	0.022 (0.847)	-0.028 (0.809)

Table 2. Correlation between family QoL (DFI) and psychological factors (SWLS, PANAS, and K-PSI) and characteristics of parents

Values are presented as correlation coefficients (p-value).

QoL, quality of life; DFI, dermatitis family impact questionnaire; SWLS, satisfaction with life scale; PANAS, positive affect and negative affect schedule; K-PSI, Korean parenting stress index.

*Spearman correlation. [†]*t*-test. [‡]Mann-Whitney *U*-test.

Table 3. Correlation between family QoL and characteristics of children with atopic dermatitis (PedsQL 4.0, IDQoL, and CDLQI)

Variable	DFI [*]	SWLS*	PANAS positive	PANAS negative [*]	K-PSI [*]
PedsQL 4.0	-0.601 (<0.001)	0.381 (0.031)	0.197 (0.280)	-0.331 (0.065)	-0.455 (0.009)
IDQoL/CDLQI	0.519 (<0.001)	-0.241 (0.037)	-0.134 (0.251)	0.309 (0.007)	0.376 (0.001)
Duration of diagnosis	0.038 (0.738)	0.075 (0.512)	-0.071 (0.535)	-0.084 (0.465)	-0.083 (0.468)
SCORAD	0.425 (<0.001)	-0.154 (0.180)	-0.036 (0.753)	0.184 (0.108)	0.150 (0.189)
Gender [‡]	-20.071 (0.038)	-0.343 (0.732)	-0.574 (0.568) [†]	-0.312 (0.755)	-0.710 (0.478)
Age	-0.183 (0.109)	-0.012 (0.858)	-0.003 (0.979)	0.080 (0.484)	-0.178 (0.119)

Values are presented as correlation coefficients (p-value).

QoL, quality of life; PedsQL 4.0, pediatric quality of life inventory version 4.0 generic core scale; IDQoL, infants' dermatologic quality of life; CDLQI, children's dermatology life quality index; DFI, dermatitis family impact questionnaire; SWLS, satisfaction with life scale; PANAS, positive affect and negative affect Schedule; K-PSI, Korean parenting stress index; SCORAD, scoring of atopic dermatitis.

*Spearman correlation. [†]*t*-test. [‡]Mann-Whitney *U*-test.

Table 4. Logistic regression analysis to predicting family quality of life among parents of children with atopic dermatitis

Characteristic	β	OR	<i>p</i> -value	95% CI
Parents' gender	0.484	1.62	0.560	0.32-8.26
SWLS	0.105	1.11	0.872	0.31-3.97
PANAS negative	1.340	3.82	0.041	1.06-13.81
K-PSI	2.201	9.04	0.186	0.35-236.63
Children's gender	2.128	8.40	0.003	2.04-34.64
IDQoL/CDLQI	0.614	1.85	0.400	0.44-7.72
SCORAD	1.879	6.55	0.018	1.38–31.16

Considering DFI scores as dependent variable.

OR, odds ratio; CI, confidence interval; SWLS, satisfaction with life scale; PANAS, positive affect and negative affect schedule; K-PSI, Korean parenting stress index; IDQoL, infants' dermatologic quality of life; CDLQI, children's dermatology life quality index; SCORAD, SCOring Atopic Dermatitis.

older (mean of 61.1 months vs. median of 13 months [IQR, 7–29 months]) and the duration of AD was longer (21.0 ± 33.2 months vs. 3 months [IQR, 2–5 months]) [14]. However, the correlation analysis showed no statistically significant difference between

family QoL and children's age or duration of AD in our post hoc analysis. Another possibility may exist at sampling method. Our study participants were recruited at an outpatient clinic of a university hospital. Thus, families experiencing more difficulties

Asia Pacific allergy

with AD management might be more willing to participate in this study and this bias may lower scores of family QoL.

The results of the logistic regression analysis revealed that low family QoL was correlated with AD severity, children's gender of girls, and the negative emotionality of parents. Families of children with a high severity of AD were over 6 times more likely to have a low QoL. This finding was consistent with previous studies, which indicated that parents of children with AD is known to be associated with depression and stress [29-32].

Parents of girls with AD had lower QoL than those of boys. Our result is somewhat similar with a study [33] which reported that there was an increasing propensity of divorce among parents caring for girls with AD. Another study also noticed that girls with mild AD had significantly impaired self-perception concerning, but boys with mild AD in the same age group did not report such an impairment [34]. This is thought to be because girls tend to consider that appearance is more important. Therefore, this gender difference in perception about AD might also affect psychological response of their parents.

This study had some limitations. Because the participants were selected through a university hospital among children with AD and their parents, they are not representative of all AD patients; therefore, it is difficult to generalize the findings of this study.

In conclusion, this study explored how the family QoL was affected by various factors focusing on parents' psychological characteristics and children's AD severity. Impaired family QoL was positively correlated with AD severity, parent's negative emotionality, and children's gender of girls.

This study results provided new insight into family QoL influenced by parents' psychological characteristics. Parents who have negative emotionality may show lower Family QoL. Thus, it is necessary to consider emotional supporting of parents in long journey of AD management.

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