

The influence of childhood atopic dermatitis on health of mothers, and its impact on Asian families

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This study examines maternal perceptions of paediatric atopic dermatitis (AD) on family and determines risk factors including severity of AD, maternal physical and mental health (MH), quality of life of patients and sociodemographics which predict a negative family impact. A cross-sectional assessment using the Dermatitis Family Impact Questionnaire Scale to assess the impact of AD on family, Infant's Dermatitis Quality of Life Index (< 5-yrs old) or Children's Dermatitis Life Quality Index (5–17 yrs old) was used to measure health-related quality of life (HRQOL) of paediatric patients with AD. A 12-item Short-Form Health Survey (SF-12) was used to assess physical and MH of their mothers. Risk factors of adverse family impact were assessed using multiple regression analysis. One hundred and four patients with AD and their mothers were studied. Their mean ages ($\pm$ s.d.) were respectively 6.4 ± 4.3 and 37.2 ± 6.6 yrs. In multiple regression analysis, Severity Scoring of Atopic Dermatitis (SCORAD) appeared to be associated with negative family impact and the association remained significant after adjustment for bio-psycho-social factors and HRQOL of patients. The association remained insignificant after adjustment for physical and MH of the mothers. Our results show that the severity of paediatric AD leads to negative family impact through reduction of physical and MH of the mothers, and is independent of patients' HRQOL and sociodemographics. The current approach for managing paediatric AD in Asian society could include early multidisciplinary intervention, aiming at enhancing physical and MH of mothers while minimizing negative impact on family and social isolation. Further research will be welcomed as the results of this study mainly applied to Asian society which could be different to populations from other geographic areas.

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Paediatric atopic dermatitis (AD) is a common skin condition affecting 15.4% of infants and 20.8% of school children (1, 2). The extensive involvement of skin, the hassle for chronic treatment, loss of income with increased child care costs and restriction in activities may have adverse effects on the family (3). Fennessy et al. (4) reviewed the current research findings and health policy on childhood AD and concluded that physicians tend to focus on physical aspects

of AD and family impact is underestimated when the disease improves.

Previous studies exploring the relationship between childhood AD and family impact in western countries generated the following research findings: Mothers looking after children with moderate to severe AD have equivalent high stress level as mothers looking after children with severe developmental and physical problems (5). Mothers of infants with AD displayed more

negative emotional behaviour such as depression and anxiety compared with normal controls (6). Compared with looking after a child with chronic asthma, caring for a child with chronic AD was associated with greater parental sleep disturbances. Disruption to parental sleep correlated with anxiety levels in both parents and depression scores in mothers (7). In addition, the quality of family life (8) and impact on the family (9) were found to be related to the severity of paediatric AD. Parent–caregiver’s estimate of severity of AD was found to be the single strongest predictor of family impact before and after dermatological care for their children (10). In Asia, Aziah et al. (11) confirmed that the family impact and children’s quality of life impairment were shown to be greater in severe AD compared with moderate AD. The health-related quality of life (HRQOL) of mothers and the potential mediators for negative family impact remain unknown among Asian children with AD.

Singapore, a South-east Asian city state with a population of 3.8 million, has a multiethnic group composition consisting of 77% Chinese, 14% Malays and 8% Indians. The rapid urbanization and westernized lifestyle accounts for the high prevalence of paediatric AD (2). This study focused on the perceptions of AD by mothers as main caregivers and the impact of paediatric AD on their family. It was hypothesized that severity of paediatric AD and negative family impact were directly related, and we identified the mediating factors for negative family impact.

Methods

Population

This study included 104 consecutive patients with childhood AD during their visits to the National Skin Centre between April 2007 to February 2008. There were two sets of inclusion and exclusion criteria respectively for mothers and patients. Mothers were included if they were: (i) equal or older than 21 yrs of age, (ii) being able to read English, (iii) the main caregiver. Mothers were excluded if they were: (i) suffering from chronic medical illness(es) or (ii) looking after immediate family members who suffered from chronic medical illness(es). Patients were eligible if they were (i) aged from 0- to 16 yrs old and (ii) fulfilling the Hanifin and Rajika criteria (1980) for AD. Exclusion criteria for the children included: (i) the presence of other chronic medical illness(es) and (ii) learning disability. One hundred and ten families meeting the criteria

were contacted and 104 (94.5%) gave informed written consent. At the visit, mothers completed a demographic information questionnaire, measures of family impact, perception of physical and mental health (MH) and HRQOL for infants (if younger than 5 yrs). Children were interviewed separately and completed a cartoon version of HRQOL scale if ≥ 5 yrs. The present study was approved by the Ethics Committee of our institution. We collected information on the maternal age, ethnic group, educational status, housing types, marital and working status, gross monthly income, family income, family history of eczema, number of children, assistance with domestic helpers and mother’s self report on compliance of medication for AD.

Atopic dermatitis – severity

Atopic dermatitis severity (mild, moderate and severe) was assessed by the Severity Scoring of Atopic Dermatitis (SCORAD) Index (12). The score was determined on the basis of several criteria, including lesion spread and intensity as well as subjective signs. As SCORAD scores vary with the stage of a treatment course. All patients were assessed during a course of treatment. The clinicians in charge assessed the extent (i.e. affected skin area) and intensity (e.g. oozing or erythema). Subjective symptoms such as sleep loss and pruritus were graded by the mothers (if patients ≤ 5 yrs old) or patients (≥ 5 yrs old). Scores ranging from 0 to 20 were classified as mild AD, scores from 21 to 40 were classified as moderate and scores from 41 to 103 were considered as severe (13).

Health-related quality-of-life of patients

The cross-sectional evaluation of HRQOL of the infants (< 5 yrs old) and children (5–16 yrs old) were performed using Infant’s Dermatitis Quality of Life Index (IDQOL) and CDLQI respectively. IDQOL is completed by the child’s regular caregiver while CDLQI has a cartoon version which is child-friendly and completed by the child. Both questionnaires contain 10 questions covering severity of itchiness, sleep and emotional disturbances, impact of leisure activities and burden of treatment over the last week. The maximum score for each question is 3, making a maximum possible score of 30. A total score of 0–5 was considered as a normal quality of life, 6–10 as low alteration in quality of life, 11–20 as moderate and > 20 as high (13). Cronbach’s alpha of 0.86 was computed for both IDQOL and CDLQI. The use of these questionnaires allowed

us to compare our study population to a previously reported population.

Physical and mental health of mothers

The physical and MH of mothers was measured by 12-item Short-Form Health Survey (SF-12). It contains 12 items, clustered into the following eight domains (14): physical functioning (PF, two items), role-PF (two items), bodily pain (one item), general health perception (one item), vitality (one item), social functioning (SF, one item), role-emotional functioning (two items) and MH (two items). The score on mental and physical health ranges from 0 to 100, with a lower score indicates poorer health or functioning.

Family impact

The Dermatitis Family Impact Questionnaire (DFIQ) consisted of 10 questions regarding the influence of the child's AD on housework, meal preparation, sleep, family activities and entertainment, shopping time, expenses, tiredness, mood and relationship between family members (15). Each question was assigned a score from 0 to 3, with a maximum score of 30. A total score of 0–5 was considered as normal, 6–10 as minor alteration in family, 11–20 as moderate and >20 as high (13). Cronbach's alpha of 0.89 was computed for this sample.

Statistical analysis

Descriptive statistics of each risk variable were generated and the one-way ANOVA was performed to compare parametric variables among different family impact groups and to determine possible predictors. For data which did not follow a normal distribution, Kruskal–Wallis test was used instead. Data were analysed by the Pearson correlation coefficient for any association between SCORAD, HRQOL of patients, SF-12 PH, SF-12 MH and DFIQ. Univariate linear regression analyses were conducted to examine the unadjusted association between SCORAD and family impact. In multiple regression analyses, the models were further adjusted for potential bio-psycho-social mediating and confounding factors in the SCORAD – family impact association. Unstandardized coefficients and their corresponding s.e. were computed. The level of statistical significance was set at $p < 0.05$, two-tailed. All analyses were performed using SPSS version 14.0 software (Statistical Package for Social Science 14.0; SPSS Inc, Chicago, IL, USA).

Results

Descriptive characteristics

Participants included 104 children (57% boys and 43% girls) with a mean age ($\pm$ s.d.) of 6.4 ± 4.3 yrs who suffered from mild to severe AD (16% mild, 40% moderate and 44% severe). The characteristics of the 104 mothers of children with AD are summarized in Table 1. None of the patients were hospitalized for AD or require systemic immunosuppression. Analysis of the mean scores of individual items from the IDQOL/CDLQI questionnaires revealed that the three elements which made up the greatest causes of discomfort for the infants were: (i) itching, (ii) sleep problems, (iii) the influence of the disease on the infant's mood. For the children, the four most disturbing elements were

Table 1. Demographic characteristics of mothers looking after paediatric AD patients (n = 104)

	n (%)
Age at interview (yrs)	
<30	14 (13.5)
30–39	55 (52.9)
>39	35 (33.6)
Ethnic groups	
Chinese	72 (69.2)
Malay	19 (18.3)
Indian	9 (8.7)
Others	4 (3.8)
Marital status	
Married	101 (97.1)
Separated	2 (1.9)
Divorced	1 (1)
Never married	0 (0)
Educational status	
No education or primary school	7 (6.7)
Secondary school	44 (42.3)
Junior college or polytechnics	12 (11.5)
University	41 (39.5)
Housing	
1–2 room public housing estate	0 (0)
3–4 room public housing estate	9 (8.7)
Executive flats/private properties	95 (91.3)
Working status	
Not working	36 (34.6)
Part time	8 (7.7)
Full time	60 (57.7)
Monthly family income (SGD)	
<1000	2 (1.9)
1000–3999	47 (45.2)
4000–6999	24 (23.1)
7000–9999	14 (13.5)
>10 000	17 (16.3)
With the assistance of domestic helper	
No	67 (64.4)
Yes	37 (35.6)

On average, one US dollar was exchanged for 1.36 Singapore dollars (SGD) through 2008–2009, and one EURO was exchanged for 2.16 Singapore dollars (SGD) through 2008–2009.
AD, atopic dermatitis.

(i) itching, (ii) sleep problems, (iii) impact on swimming and sport, (iv) inconvenience because of treatment. For the mothers, the greatest problems in their physical and MH include (i) limitation of moderate activities such as housework, (ii) less accomplishment because of poor physical or emotional health, (iii) reduction of social activities like visiting friends and relatives. The ratings made by the mothers on the family impact are shown in Fig. 1.

Relation between the severity of atopic dermatitis and family impact

Table 2 shows the bio-psycho-social characteristics of patients and mothers of different levels of family impact. Poorer HRQOL of patients ($p < 0.001$), poorer physical health ($p < 0.05$) and MH ($p < 0.001$) of the mother were significantly more common in families with higher impact. Table 3 shows the correlation coefficient between SCORAD (mean $\pm$ s.d.: 41.6 ± 25.3 , interquartile range: 22.5–59.6), HRQOL of patients (mean $\pm$ s.d.: 8.5 ± 5.8 , interquartile range: 4–12.3), SF-12 PH (mean $\pm$ s.d.: 52.7 ± 4.8 , interquartile range: 51–55.4), SF-12 MH (mean $\pm$ s.d.: 49.7 ± 8.8 , interquartile range: 44.8–56) and DFIQ (mean $\pm$ s.d.: 7.2 ± 6.5 , interquartile range: 2–10). The SF-12 PH ($r = -0.22$, $p < 0.05$), SF-12 MH ($r = -0.24$, $p < 0.05$) and DFIQ scores ($r = 0.35$, $p < 0.01$) are modestly and significantly correlated with SCORAD.

Table 4 shows the association between SCORAD and family impact. SCORAD was associated with negative family impact ($\beta = 0.089$, s.e. = 0.024, $p < 0.001$). After adjustment for sociodemographic status, duration of AD, total number of children and HRQOL of

patients, the association between SCORAD and negative family impact remained statistically significant ($\beta = 0.066$, s.e. = 0.028, $p < 0.05$). After adjustment for physical and MH of mothers, the association between SCORAD and negative family impact were insignificant ($\beta = 0.037$, s.e. = 0.027, $p = 0.17$).

Discussion

The results of this study give a better insight into the perceived impact of paediatric AD on families from a maternal perspective, identifying associated predictors for negative family impact. Our results suggest that, paediatric AD has a negative impact on everyday life of Asian families, particularly if associated with greater severity of AD, and a poorer physical and MH of mothers and patients. Through multiple regression analysis, our findings confirm that severity of paediatric AD leads to a negative family impact through deterioration of maternal physical and MH, but independent of patients' HRQOL and sociodemographics.

Paediatric AD is characterized by recurring skin rashes affecting patients and families whole day long. During daytime, mothers reported an increase in the normal burden of washing, dusting and cleaning to avoid allergens (16). The extra household chores may make mothers tired with body pain, leading to reduction of activity level and less accomplishment, as reported in our subjects. The mothers may have less resources and time to look after other family members. Despite emotional distress, the majority of mothers in this study did not report being less careful as the care of patients require high attention level. The mothers in this study reported reduction in social activities, such as visiting friends or relatives which may lead to isolation of both mothers and their family. This finding may be also related to upward comparison as it is not uncommon for mothers of children with AD to compare with their friends and relatives whom children are healthy. This comparison may lead to difficult feelings and avoidance. During the nighttime, AD is often related to sleep disturbances in patients and parents, causing daytime drowsiness in family members. In our sample, paediatric AD had the greatest impact on expenditure as families often face financial difficulties in terms of loss of income because of time off work, travelling costs to the clinics, child care costs for siblings, specialist clothing, bedding and equipment (3).

Some of our findings were similar to those found in the western countries. Firstly, the

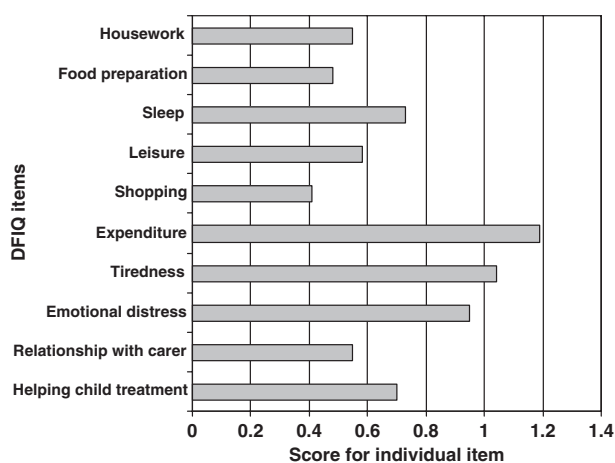


Fig. 1. Scores of individuals items from Dermatitis Family Impact Scale (n = 104).

The influence of childhood atopic dermatitis on health of mothers

Table 2. Bio-psycho-social characteristics of patients and mothers of different levels of family impact (n = 104)

	No family impact	Family		Impact	p-Value
		Low family impact	Moderate family impact		
No. families	51	28	19	6	
Mean age of mothers (yrs)	38.57	36.54	34.63	36.50	0.14
Marital status (% married or staying with partner)	96.1	96.4	100	100	0.77
Mean age of children (yrs)	6.88	6.56	4.84	6.35	0.36
Mean onset age of AD (yrs)	2.84	3.30	2.22	2.21	0.68
Mean duration of AD (yrs)	4.35	3.47	3.47	4.14	0.68
Gender of children (% of boys)	62.7	64.3	31.6	50.0	0.07
Ethnic groups of children (%)					
Chinese	68.6	75.0	68.4	50.0	
Malay	13.7	17.9	26.3	33.3	0.90
Indian	11.8	3.6	5.2	16.7	
Others	5.9	3.6	0	0	
Housing (%)					
1–2 room	0	0	0	0	
3–4 room	13.73	7.14	0	0	0.75
Private	86.27	92.86	100	100	
Gross monthly income (%)					
<\$1000	2.0	3.6	0	0	
\$1000–3999	49	46.43	31.58	50.0	
\$4000–6999	15.69	21.43	42.11	33.33	0.20
\$7000–9999	11.76	14.29	15.79	16.67	
>\$10 000	21.57	14.29	10.53	0	
Mean no. children	2.27	2.21	1.74	1.67	0.07
Compliance (%)					
<50	0	0	0	0	
50–70	2.2	4.0	7.7	0	0.75
>70	97.8	96.0	92.3	100	
Assistance from domestic helper (%)	43.1	28.6	31.6	16.7	0.53
HRQOL of children	6.20	8.68	12.00	15.50	<0.001
Physical health of mothers	53.26	52.89	52.81	46.46	0.012
Mental health of mothers	53.75	49.42	42.02	41.53	<0.001

1–2 room, 1–2 room public housing estate; 3–4 room, 3–4 room public housing estate; HRQOL, health-related quality of life.

Table 3. Correlations among demographic, SCORAD and HRQOL variables (n = 104)

	Age of child	Onset age	HRQOL (Patients)	SCORAD	SF 12 PH	SF12 MH	DFIQ
Age of child	1.00						
Onset age	0.62**	1.00					
HRQOL (patients)	0.15	0.03	1.00				
SCORAD	0.24*	0.08	0.51**	1.00			
SF 12 PH	0.03	–0.27	–0.10	–0.22*	1.00		
SF12 MH	0.18	0.25*	–0.31**	–0.24*	0.05	1.00	
DFIQ	–0.96	–0.38	0.48**	0.35**	–0.24*	–0.52**	1.00

*p < 0.05; **p < 0.01.

HRQOL, health-related quality-of-life; SCORAD, Severity Scoring of Atopic Dermatitis; SF 12, 12-item Short-Form health survey; PH, physical health; MH, mental health; DFIQ, Dermatitis Family Impact Scale; HRQOL (patients) = scores from IDQOL (Infant's Dermatitis Quality of Life Index) or CDLQI (Children's Dermatology Life Quality Index).

maternal SF-12 scores did not correlate with the age of their children (9). Secondly, the higher disease severity of the children was associated with higher family impact and this could suggest a dose–response relationship (8, 9). Thirdly the three greatest problems found in our patients (mean age = 6.4) were (i) itching, (ii) sleep disturbances, (iii) influence of the disease on the infants' mood while the three

greatest problems faced by family were: (i) high expenditure, (ii) tiredness of parents, (iii) emotional distress in parents. Ricci et al. (13) reported the same findings in Italian infants (mean age = 2 yrs) and their parents. High concern for financial issue was consistent with previous studies which documented a high economic burden on the affected families with AD (17).

Table 4. Association of SCORAD Score and family impact

	All subjects (n = 104)		p-Value
	β	s.e.	
Unadjusted	0.089	0.024	<0.001
Adjusted:			
Model 1: adjusted for sociodemographic characteristics (age of mothers, duration of AD, total number of children, housing, monthly income)	0.098	0.026	<0.001
Model 2: model 1 + HRQOL of patients*	0.066	0.028	0.02
Model 3: model 2 + Physical health of mothers†	0.053	0.028	0.06
Model 4: model 3 + Mental health of mothers‡	0.037	0.027	0.14

Parameter estimates (β) are presented with s.e.

HRQOL, health-related quality-of-life; SCORAD, Severity Scoring of Atopic Dermatitis; SF 12, 12-item Short-Form Health Survey.

*IDQOL/CDQOL.

†SF-12 physical health.

‡SF-12 mental health.

Our study also yielded findings different from previous studies in paediatric AD: we found that disease severity of the children was negatively correlated with the SF-12 scores of the mothers while Warschburger et al. (9) found that SF-12 scores of both parents were not shown to be affected by the child's illness in a group of younger German children (mean age = 3.8). The differences could indicate that caring for older children may lead to more negative impact on the maternal HRQOL. The other explanation could lie in the differences in between maternal and paternal HRQOL. Our study focused solely on the mothers and this could identify more impairment in maternal HRQOL while other studies measured HRQOL of parents in general (8). Furthermore, families in our study considered reported relatively less effect on the time spent on shopping and leisure activities while these were the two commonest problems facing the British families with older children with AD (mean age = 8) (8). These differences could suggest that caring for older children lead to more impairment on family activities while caring for younger children lead to more emotional distress and exhaustion. Results from this study are also different from findings in other chronic diseases. Reynolds et al. (18) reported that children on haemodialysis were less likely to have friends, but our study found that friendship is the least disturbing issue for children with AD. This could be as a result of differences in treatment setting between the two disorders as renal patients often go to a dialysis centre three times per week which may lead to significant disruption in school attendance and interaction with peers.

The strengths of our study include: (i) direct recruitment from clinicians followed by face-to-face interview with high recruitment rate, (ii) direct evaluation of HRQOL from children older

than 5 yrs as Walker et al. (19) highlighted the disparity between children with severe AD and their parents on happiness, social isolation and peer popularity, (iii) computation of SCORAD scores by combination of objective assessment by clinicians and subjective symptoms. An objective assessment is important as parents often cannot distinguish whether their child was significantly affected by AD or not (19).

Nevertheless, our study has a number of limitations. Firstly, this study has a small sample size and infants and children were grouped together (n = 104) for analysis. Secondly, the current study is a cross-sectional examination of family impact, concrete inferences regarding cause and effect cannot be made. Thirdly, this study focused on maternal perceptions and it would be useful for further studies to explore the impact on fathers and siblings. Fourthly, this study adopted a quantitative approach which did not include qualitative responses. Positive and negative parental appraisals of the family impact can co-exist and further research is required to understand the protective factors and resilience on families coping with paediatric AD (20). The results of this study suggest that further evaluation on the effect of holistic approach involving psychosocial services to caregivers focusing on mental and physical health, financial counselling, psychoeducation and psychotherapy is necessary. The long-term treatment goal is to assist the family to develop a positive appraisal of the demands of child caregiving and this will help parents to sustain their efforts over long-period (21).

In conclusion, severity of paediatric AD is associated with a negative impact on the family through worsening of physical and MH of the mothers but independent of HRQOL of patients and sociodemographics. Interestingly,

the Singaporean and Italian families are mainly affected in the same areas including high expenditure, tiredness and emotional distress in parents. Further research will be welcomed as the results of this study mainly applied to Asian society which could be different to populations from other geographic areas. Further evaluation is necessary for interventions such as individual therapy, support group, psychoeducation and family therapy on psychosocial well-being of mothers as part of the disease management program for paediatric AD.

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