

ORIGINAL ARTICLE

Disease severity and associated family impact in childhood atopic dermatitis

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Aim: To examine the association between childhood atopic dermatitis (AD) severity and family impact at baseline and after an intervention by a physician specialist, using validated measures of both severity and family impact.

Methods: Cross sectional self administered survey of parent-caregivers of 49 randomly selected children with AD; 35 parents were available for follow up. Family impact was measured using a modified AD Family Impact Scale completed by the parent-caregiver. The child's disease severity was measured using both the investigator's assessment via the Eczema Area and Severity Index (EASI) and the caregiver's assessment via the recently validated Self Assessment Eczema Area and Severity Index (SA-EASI).

Results: The parent-caregiver's assessment of severity of the child was the most significant correlate of the family impact of the child's AD ($p = 0.65$ at baseline and $p = 0.38$ at follow up). In multivariate regression models, the parent-caregiver's estimate of severity remained the single strongest predictor of family impact before and after receipt of dermatologist care, as well as the difference in impact between pre and post-dermatologist care.

Conclusions: There is evidence to support the ability of parent-caregivers of children with AD to accurately determine severity of their child's AD; perceived severity is the driver of the family impact of this condition. Treatment of a child by a physician specialist is associated with reductions in both perceived severity, as well as family impact of this condition.

Atopic dermatitis (AD) is a chronic skin condition of both children and adults and may affect 5–20% of children up to 11 years of age at one time or another.¹ This disease has significant quality of life (QOL) and economic consequences, which are not limited to the patient, but extend to the entire family unit.² As one of the most common skin conditions of childhood, AD has been associated with lowered QOL in children as well as family members. AD in children can disrupt family and social relationships, in addition to interfering with recreational activities and school. Parents have reported both high stress related to treating and taking care of the child with AD and feelings of helplessness regarding the child's symptoms.³ In a German study comparing infants with AD to normal infants, mothers of infants with AD showed more anxious and overprotective attitudes when surveyed.³ In addition, the burden of caring for the child with AD can negatively affect spousal relationships and interfere with giving adequate attention to siblings.^{2,4,5} It has even been proposed that the decreased quantity and quality of maternal touching may affect the child's development, leading to behavioural problems and worsened AD because of life stress.⁶

In order to reduce the family and psychosocial difficulties associated with AD, researchers and clinicians must first have a clear understanding of the ramifications of the child's disease severity. Secondly, one must examine how AD impacts different areas of family functioning. Armed with these two pieces of data, researchers and clinicians can determine the relation between the two (disease severity and family impact) in order to determine whether particular treatments or interventions can help decrease the negative impact of AD on the family. First, disease severity has traditionally been measured by the investigator using the Eczema Area and Severity Index (EASI).^{7–9} Recently, a measure has been developed and validated allowing a caregiver to assess the severity of their child's AD using the Self Assessment Eczema Area and Severity Index (SA-EASI).¹² This study assessed and showed

criterion validity of the SA-EASI by comparing it to the EASI directly in 47 subjects. In addition the subcomponents of both acute and chronic SA-EASIs were compared to acute and chronic subcomponents of the EASIs to show further validity of the measure. In addition, development of the Dermatitis Family Impact (DFI) questionnaire has allowed researchers to determine the impact of AD on specific aspects of family functioning.² The DFI is a short, 10 item scale that assesses the impact of AD in areas such as housework, food preparation, leisure activities, sleep, emotions, and family relations. An individual analysis of the impact of AD on different aspects of life can therefore be made, as well as a determination of overall family impact.

Little evidence exists examining the impact of the implications of the child's disease severity on the family impact of the condition. A cross sectional comparative study by Su *et al* found that families of children with moderate or severe atopic eczema had a higher impact on family score than families of diabetic children.¹³ However, for this study the authors used the non-AD specific family impact questionnaire. In addition, severity was measured categorically by the physician. More recent studies have shown strong correlations between parents' assessment of their child's AD and physician ratings.¹² Additionally, distinct parent-caregiver perceptions have been shown to be strong drivers of family impact scores in AD.¹⁴ It therefore becomes important to reexamine this issue in the context of the parent-caregiver, as evidence exists that caregiver perceptions are strong indicators of the level of care received by children with chronic conditions.¹⁵ Findings

Abbreviations: AD, atopic dermatitis; ADFIS, AD Family Impact Scale; DFI, Dermatitis Family Impact; EASI, Eczema Area and Severity Index; OTC, over the counter; QOL, quality of life; SA-EASI, Self Assessment Eczema Area and Severity Index; VAS, visual analogue scale

Table 1 Modified Atopic Dermatitis Family Impact Scale used for study

<p>How much has your child's eczema had an effect on:</p> <ul style="list-style-type: none"> • Housework or yard work • Food preparation and eating • Sleep of other family members • Family leisure activities (for example, sports, relaxation, hobbies) • Shopping time for family • Money spent on child's condition (for example, treatment, clothes, etc) • Causing your tiredness or fatigue • Causing you emotional distress like feeling sad, anxious, or worried • Upset relationships in the family • Your life <p>Each item has four responses, which are scored as: very much (3 points), a lot (2 points), a little (1 point), not at all (0 points). Every item is equally weighted and the scale has a score range from 0 to 30</p> <p>Original scale reference: Lawson V, Lewis-Jones MS, Finlay AY, et al. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. <i>Br J Dermatol</i> 1998;138:107–13</p>
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of such studies could have policy implications for compliance with therapy, and the necessity of further medical care and behavioural interventions for children with AD and their families.

We first explored whether the investigator's assessment of AD severity using the EASI or the caregiver's assessment of the child's disease severity using the SA-EASI is associated with the family impact. We then examined whether the changes in the EASI or SA-EASI scores correlate with the family impact scores. Thus, we considered the effect on family impact as a function of the child's disease severity at baseline and after an intervention by a physician specialist.

MATERIALS AND METHODS

Study conduct

The study employed a longitudinal before-after design. Parents of children (aged 6 months to 12 years) with AD who brought their child to a dermatologist at an academic medical centre were self administered a detailed questionnaire, which contained questions about sociodemographics, perceptions about the child's health, health care service use for the child, and satisfaction with medical care received by the child. Family impact of the child's condition in the week prior to questionnaire response was measured using a slightly modified version of the 10 item DFI, henceforth referred to as the Atopic Dermatitis Family Impact Scale (ADFIS) (table 1).² At the same visit, the child's disease severity was assessed by an investigator using a modified EASI scale and by the caregiver using the SA-EASI. A repeat questionnaire examining treatment satisfaction and family impact was administered in a month, when the child was brought in for a follow up visit. At the follow up visit, AD severity was again assessed using the modified EASI and the SA-EASI. If the child was not scheduled for a follow up visit, the follow up questionnaire and SA-EASI were mailed to the parent. Informed consent was obtained from all participants, and conduct of the study was approved by the Institutional Review Board. A diagnosis of AD was confirmed by cross review with the medical chart after the child's visit. We excluded parents who had children with major medical illnesses that required constant attention, as these conditions would potentially lead to overstatement of the family impact of AD, as well as those parent-caregivers who could not complete the survey. The study was limited to a small sample because of its exploratory nature and the limitations associated with recruitment of subjects from busy clinical offices.

Study instruments and variables

The 47 item baseline questionnaire included questions on demographics (age, race, insurance status, education, marital status, employment); caregiver characteristics (children with chronic conditions, decision making for child's care, work days

lost because of child's condition, rating of child's AD severity, willingness to use non-medical services (OTC products and cosmetics, humidifiers, air filters, etc) for child's condition, financial and transportation concerns for child's medical care, satisfaction with medical care and physicians treating child in the past six months); and family impact (10 item ADFIS modified for US subjects). The follow up questionnaire was comprised of 21 questions primarily focused on measuring treatment satisfaction, changes in health behaviour, and family impact.

Many of the questions (including parent perception of severity) were recorded using a Likert scale (such as all the time, most of the time, sometimes, never; or very severe, severe, moderate, mild). These responses were categorised into bivariate (yes/no) responses, utilising the extreme two categories (for example, most of the time or all the time in one category to represent adherence to a behaviour, and severe or very severe to represent parent's perception of severe disease) to simplify the analyses as well as to account for the limited statistical power of the study. For other variables, we used the most of the time and all the time variables to categorise a patient, such as being financially concerned or having transportation problems.

The one page SA-EASI consisted of two parts. To estimate the surface area involved, a line drawing silhouette of the front and back of a body was presented to the caregivers, and they were instructed to shade in the areas currently affected by AD. Based on the silhouette shading, a single investigator who had not evaluated these patients assigned a numeric value of 0–6 corresponding to 0–100% body surface area involvement for each of the following four areas: head, upper extremities, trunk, and lower extremities. The second part of the one page, SA-EASI instrument consisted of five modified 100 mm (10 cm) visual analogue scales (VASs). The VAS consists of a continuous line on which the caregiver makes a mark to signify the average severity of the child's AD lesions. The VAS scales enabled caregivers to describe the redness, thickness, dryness, number of scratches, and itchiness of an "average" AD lesion. On each VAS, extremes and intermediate levels were labelled with anchor marks at equivalent intervals along the VAS line. The validation of the SA-EASI and modified EASI instruments and their scoring have been previously described in detail elsewhere.¹²

Statistical analyses

Descriptive statistics (frequencies, means, and percentages) were used to describe the baseline time invariant sociodemographics of the study population. Paired *t* tests were conducted to examine changes in the time variant parent-caregiver characteristics, parent and physician rated severity, as well as the ADFIS score pre and post-specialist visit. Variables that were statistically significant ($p < 0.10$) in the paired *t* tests

Table 2 Sociodemographic characteristics of study population

Characteristics	Baseline (n=49) Mean (SD)	Follow up (n=35) Mean (SD)
<i>Demographics</i>		
Age of caregiver (in years)	30.3 (8.1)	29.9 (6.5)
Age of child (in years)	4.7 (3.4)	5.0 (3.7)
Non-white race (%)	49.0	45.7
Hispanic origin (%)	4.1	5.7
Parent-caregiver mother (%)	89.8	94.3
Parent-caregiver at least high school educated (%)	89.8	88.6
<i>Parent socioeconomic</i>		
Parent-caregiver employed (%)	89.8	91.4
Parent-caregiver single marital status (%)	34.7	37.1
Has public insurance for self/child (%)	30.6	34.3
Has private insurance for self/child (%)	51.0	51.4
Total annual family income less than \$20000 (%)	28.6	31.4
Problems with insurance coverage of essential medical services for child (%)	20.4	14.3
<i>Parent-caregiving issues</i>		
Has other children with skin conditions (%)	18.4	11.4
Children have other chronic conditions (%)	22.4	25.7
Feels that she/he should be primary decision maker in child's health care (%)	28.6	20.0
Number of years of caring for child's condition	3.4 (3.3)	3.5 (3.3)
Concerned about financial implications of caring for child's condition (%)	34.7	31.4
Transportation problems seeking care for child (%)	16.3	14.2

Standard deviations, where applicable, are indicated in parentheses.

Table 3 Parent-caregiver characteristics at baseline and follow up

Characteristics	Baseline	Follow up
<i>Parent-caregiving issues</i>		
Lost more than a day in work last month because of caring for child's condition (%)	14.3	11.4
Perceives child's condition is severe (%)**	45.7	2.9
High use of services beyond medical treatment for child's care (%)*	14.3	2.9
<i>Outcomes</i>		
Total EASI score (physician rated)**	30.8 (28.6)	12.7 (14.8)
Total SA-EASI score (parent rated)**	18.2 (19.4)	6.9 (5.7)
AD Family Impact Scale score**	10.0 (7.5)	5.7 (4.1)

Standard deviations, where applicable, are indicated in parentheses.

*p<0.05; **significant at p<0.01 across two time periods using paired t tests.

were retained for the multivariate model (multiple regression analysis), examining the confounder adjusted association of severity with family impact for baseline and follow up data.^{16,17} A separate multiple regression analysis (detailed results not shown) was conducted to examine how changes in time variant parent-caregiver characteristics and severity after the specialist visit were associated with changes in the ADFIS scores. The dependent variables in the bivariate multivariate estimations were the ADFIS score (range 0–30) and changes in ADFIS score respectively. All statistical analyses were conducted using STATA statistical software.¹⁸

RESULTS

A total of 68 subjects were contacted over a three month period. Ten subjects were excluded from further study participation because they did not meet the inclusion criteria, and nine refused to participate. Fourteen subjects were not available for follow up. A total of 49 subjects completed baseline interviews and 35 completed baseline and follow up surveys. Table 2 outlines the characteristics of the survey respondents. In nearly 90% of cases, the caregiver completing the questionnaire was the mother. In the remaining cases, the respondents were foster parents or relatives. Twenty six per cent of these caregivers were bringing their child to the dermatologist's office for the first time. The mean caregiver age was 30 years and the mean age of the child with AD was 5 years. Most of the parent-caregivers had at least a high school education, and were employed.

Table 3 outlines the analyses of variance examining differences in parent-caregiver characteristics, disease severity (physician and parent rated), and ADFIS scores before and after the specialist visit. There were significant reductions in the post-specialist period in the caregiver reporting the child's AD as severe, and caregivers reporting high out of pocket expenses beyond medical treatment for child's care (over \$200 in past month on OTC products and other household expenses (air filters, humidifiers) for child's condition) (both p < 0.01). The EASI and SA-EASI scores reduced by 59% and 62% respectively in the post-baseline visit (p < 0.001). The ADFIS scores reduced by 43% in the post-baseline visit (p < 0.001). In results not shown in detail, we found strong correlations between parent and physician rated severity (p = 0.62, p < 0.001). Significant positive correlations were observed between the SA-EASI scores and the ADFIS scores (p = 0.62, p < .001 at baseline and p = 0.38, p < 0.05 at follow up).

Table 4 describes the results of the confounder adjusted multiple regression analyses for baseline and follow up data. The EASI scores were not included in the analyses, because of multicollinearity problems with inclusion of both EASI and SAEASI scores as predictors in the same model. The SA-EASI score was the only variable significantly associated (p < 0.05) with the ADFIS score in both time periods. Other factors that were significantly associated with the ADFIS score in the baseline visit included workdays lost caring for the child, and parent bringing the child to the specialist for the first time. At the follow up visit, the other factors significantly associated with the ADFIS score were the high use of services beyond

Table 4 Regression analysis examining the association between severity of AD and ADFIS score at baseline and follow up

Predictor variables	Dependent variable				
	Atopic Dermatitis Family Impact Scale score (baseline)			Atopic Dermatitis Family Impact Scale score (follow up)	
	β (SE)	p value	β (SE)	p value	
SAEASI score	0.17 (0.037)	<0.001	0.21 (0.085)	<0.05	
Parent's perception that child's eczema is severe	0.012 (1.65)	NS	0.41 (0.73)	NS	
Financial concerns in paying for medical care for child	2.40 (1.69)	NS	3.30 (1.54)	<0.05	
Work days lost because of caring for child's condition	4.91 (2.29)	<0.05	-1.13 (2.01)	NS	
High use of services beyond medical treatment for child	1.83 (3.01)	NS	9.12 (2.05)	<0.001	
New to specialist care	-5.57 (1.44)	<0.001	0.059 (1.50)	NS	
Constant	6.39 (1.35)	<0.001	2.97 (0.82)	<0.001	
Adjusted R ²	0.69		0.43		

Parameter estimates (β) are presented with standard errors (SE) indicated in parentheses. NS indicates not significant at the 0.05 level.

medical treatment for the child and financial concern over medical care payments for child. Similarly, the regression examining predictors of changes in ADFIS scores showed a strong association between decreased severity and decreased family impact scores ($p < 0.01$). We found weak to moderate correlation between parent perception of severity and SA-EASI scores ($r = 0.45$, $p < 0.01$). At the second visit we found no correlation between perception and assessment of severity ($r = 0.12$, $p > 0.05$).

DISCUSSION

This study represents one of the initial efforts to attempt to understand the association between disease severity and family impact of AD using AD specific instruments of both severity and family impact. Strong associations were found between increased disease severity and higher family impact of AD. Other salient findings included striking similarities between physician and parent assessed severity and decrease in both severity and family impact after an episode of care by a physician specialist. Of special note is the significant association between family impact and disease severity, holding even after an episode of care by a physician specialist. However, the significance of the association decreased in the post-baseline period. The parent severity assessment was not significantly associated with the ADFIS. One reason for this may be that the SA-EASI is a validated, comprehensive, and objective assessment of disease, while the perception was measured only subjectively by one item in a questionnaire.

Reductions in both the parent-caregiver's assessment of disease severity as well as family impact could have significant implications for outcomes in children with AD. In other chronic conditions such as cerebral palsy, parent-caregiver perceptions have been shown to affect both levels of health care services the child receives as well as maintaining the continuum of care.¹⁵ This study found that a parent-caregiver is able to assess the severity of his/her child's condition, and may be affected by it in their day to day functioning and family life. A parent-caregiver of a child with a chronic condition such as AD serves as an important interface in ensuring receipt of medical care and in turn, optimal management of disease symptoms and outcomes for the chronically ill child. This study for instance, found that at follow up, the non-severity related factors that were related to family impact changed with treatment. Initially, the impact of the child's condition on work schedules and unfamiliarity with specialised care seemed to be driving family impact, while in the follow up visit, costs related to caring for the child and financial concerns about treatment seemed to be drivers of family impact. The results of the study suggest that an episode of specialist care decreases family impact and perceived disease

severity; it also seems to increase the parent-caregiver's knowledge about treatment options, and associated financial burden of medical care.

Therefore, the study of caregiver burden becomes a potentially important issue. A less burdened caregiver is potentially more likely to adhere to treatment guidelines for the child, as well as ensure optimal availability of care for the child. A theoretical model for this study drew on Shapiro's four quadrant model of control which explores some of the coping strategies which are used by parents caring for children with chronic illnesses.¹⁹ This line of work suggests that parents who engage in healthy coping strategies have more positively oriented health perceptions for their child.²⁰ Educational efforts are needed to help parent caregivers identify symptoms that need expeditious medical intervention by appropriate medical care personnel, so that the outcomes in both the child and the significantly burdened parent caregiver can be improved. The self assessment of disease severity and family impact using validated instruments offers parent-caregivers and medical care professional valuable tools to track condition changes over time, even without constant medical supervision, and to develop interventions aimed at reducing the caregiver burden and improving outcomes in children with AD.

This study should be considered only an initial exploration of these issues, and caution should be exercised in interpreting these findings, because of a number of study limitations. Firstly, because of the exploratory nature of our study, our sample size was modest. This could have affected the statistical significance of some of our findings, especially in the multivariate analyses. Our study was conducted in an academic medical centre setting, and the sample has some selection bias. In spite of this, we were able to obtain a sample with a varied case mix (table 2). Another possible bias is that subjects were administered the follow up questionnaire differently, in that some were seen for follow up and some received it in the mail. Because of this some subjects received more interaction with healthcare personnel which could alter the ADFIS. We also excluded subjects who refused to fill out questionnaires, who had children with major illnesses, and those who could not complete the forms. We were also restricted to limited parent-caregiver variables which we could examine in this exploratory analysis, because of the administration setting (busy clinician office) and timing. These limitations need to be addressed in future research to confirm the policy implications of this exploratory analysis.

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ARCHIVIST

Management of necrotising enterocolitis

Necrotising enterocolitis (NEC) and focal intestinal perforation (FIP) in preterm babies are both associated with hypoxia, indomethacin treatment, and hypertonic feeds and may be different manifestations of the same disease. Laparotomy has been regarded as standard practice but recently peritoneal drainage has been proposed, particularly for infants with FIP, in an attempt to avoid laparotomy in sick infants. Surgeons in Los Angeles (Alda L Tam and colleagues. *Journal of Pediatric Surgery* 2002;**37**:1688–91; Alfonso Camberos and colleagues. *Ibid*: 1692–5) continue to favour laparotomy and have reviewed the value of preoperative plain abdominal x rays and the results of laparotomy.

The radiological series, over the 11 years 1990–2000, included 80 infants (mean gestational age 28 weeks, mean birthweight 1170g), 61 with NEC diagnosed at surgery or autopsy, and 19 with FIP without NEC. They found that positive signs on x ray were of great diagnostic significance but the absence of these signs was of little value. For NEC, radiological pneumatosis intestinalis was 100% specific but only 44% sensitive and portal venous gas was 100% specific but 13% sensitive. For FIP free air was 92% specific and 52% sensitive and a gasless abdomen 92% specific and 32% sensitive. Others have argued that the absence of pneumatosis intestinalis on x ray suggests a diagnosis of FIP and favours treatment with peritoneal drainage.

A second review included 35 infants with birthweights under 1500 g who had undergone laparotomy for NEC (23) or FIP (12) between 1994 and 2000. Postoperative mortality by 7 days was 7/35 (20%) and by 30 days 9/35 (26%). For NEC the corresponding figures were 26% at both 7 and 30 days and for FIP 8% and 25%. Excluding five infants with pan-intestinal necrosis, who all died, reduced the overall 7 and 30 day mortalities to 6% and 11%. The authors of this paper conclude that their mortality with laparotomy was similar to the 21% to 43% reported for peritoneal drainage. They favour laparotomy because it allows direct inspection of the type and extent of disease, removal of gangrenous bowel, and diversion of the faecal stream. They point out that many (26% to 83%) infants treated with peritoneal drainage need subsequent laparotomy.