

Pediatric Atopic Eczema: The Impact of an Educational Intervention

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Abstract: Patient education has been regarded as having a key role in the self-management of atopic eczema. However, the relationship between the educational interventions and clinical outcomes including severity of eczema, quality of life, and family impact has not been rigorously examined. The purpose of this longitudinal randomized controlled study was to evaluate the impact of an intensive education program with a focus on dermatology and immunology designed for parents and children diagnosed with atopic eczema. The intention of this study was not to change treatment regimes prescribed by the patient's physician. The Scoring Atopic Dermatitis rating system was used for assessment of disease impact, and the impact on quality of life was quantified by using the Children's Dermatology Life Quality Index, Infants' Dermatology Quality of Life Index, and Dermatitis Family Impact. A total of 61 pediatric patients (0–16 years) diagnosed with atopic eczema from the metropolitan area of Adelaide were randomized to either the control or intervention group. Results of the study showed that the intervention group had a significant improvement in the scoring atopic dermatitis measure when compared to the control group at week 4 and week 12. Quality of life measures did not significantly improve with decreased severity of eczema except in the group of children aged 5–16 years which, despite small numbers, showed a significant improvement in quality of life scores. These findings suggest that education provides an important role in decreasing the severity of eczema.

Atopic eczema (AE) is a nonspecific inflammatory response of the skin to a combination of exogenous and endogenous factors and is known to affect 10–20% of children (1). Moreover, there is evidence to suggest that this prevalence is increasing (2). The disease often first becomes evident in childhood and will persist into adult life for 60% of patients (3). The condition is frequently undertreated and there remains a conservative attitude

toward the use of corticosteroids (4); despite that, AE has a large-scale emotional, social, and financial impact on the child and family (5). A comparative Australian study (6) demonstrated that moderate or severe AE has a more significant impact on families than insulin dependent diabetes mellitus.

The physical and social impact of AE may include inhibition of normal bonding between the child and the

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parent, sleep deprivation, interference with peer relationships, and school absenteeism, which interferes with learning (5). A survey of parents of children with AE found that parents experienced guilt, exhaustion, frustration, resentment, and helplessness due to their child's condition (7).

There are also economic costs associated with caring for children with AE. A study undertaken in Australia found that children with moderate AE had an average of 13 physician visits per year at a cost of about \$1700 annually for the family. Children with the severe form of eczema averaged 23 physician visits annually at an estimated cost of greater than \$2500 (6).

Patient (including parent) education has been regarded as having a key role in the self-management of this illness. Much of the literature promotes the active engagement of patients in decision making related to their care, which ultimately results in better adherence to treatment regimens (8). However, the relationship between the educational interventions and clinical outcomes including severity of eczema, quality of life (QOL), and family impact, has not been rigorously examined.

Management of AE is reliant upon severity scores that allow clinicians to monitor the course of the disease and the impact of various treatments (9). In 1993 a task force of European experts published a scoring system, known as Scoring Atopic Dermatitis (SCORAD), that incorporated both objective signs (severity and extent) and subjective signs (pruritis and loss of sleep) (10). A review of 13 scales used to measure disease severity objectively in AE found that of the severity scoring systems currently available for AE, the SCORAD index has been the most extensively tested for the quality criteria of a good scale (11).

It is widely acknowledged that standard measures of disease status insufficiently describe the personal and family burden associated with AE. Measurement of the impact of eczema on QOL is essential for clinical decision making, clinical research, and audit of dermatology services. For this reason QOL assessment has become an important outcome variable in dermatology research. QOL measurement is generally assessed by self-report questionnaires.

Adult QOL measures differ markedly from those of children. Similarly, infants require a different QOL questionnaire from the one designed for children because of immaturity in communication, and lack of concentration and ability to speak (12). The impact on children's QOL caused by AE has been quantified by using various QOL measures [Children's Dermatology Life Quality Index (CDLQI), Infants' Dermatology Quality of Life Index (IDQOL), and Dermatitis Family Impact (DFI)] (12–14). However, the relationship between these meas-

ures is poorly correlated with clinical severity (12). Only a few studies have QOL as a primary outcome measure, making it difficult to draw anything but vague conclusions (15).

Although self-management is conceptually appealing, with its links to primary health care and patient empowerment, the relationship to health outcomes is less clear. A systematic review of the efficacy of patient self-management education programs found small to moderate effects for selected chronic illnesses, namely diabetes, hypertension, and asthma (16). Research related to the effectiveness of self-management education interventions for people with AE has not been reported in the literature. However, it could be argued that self-management interventions may be effective in AE, as it is possible to define self-management goals. There are clearly defined protocols for the assessment of the severity of AE and parallel strategies for patient monitoring and adjustment of therapy.

Some encouraging findings have been reported anecdotally and in the literature that are consistent with self-management education strategies and suggest favorable health outcomes. A patient education program of adults with eczema in Sweden aimed to improve and maintain health by providing knowledge in self-care treatment of eczema (17). The study was conducted with only a small sample size of seven. However, results of the study indicated that the severity of eczema experienced by the patients improved following the education program. Another example of an effective self-management education strategy is the Paediatric Eczema Workshop conducted at the Royal Children's Hospital in Melbourne in 2002. Anecdotal evidence from staff and consumers suggests that the workshop has resulted in decreased severity of eczema, decreased outpatient waiting lists, and increased satisfaction with services. While these findings are encouraging, further research is warranted to examine the relationship between self-management education interventions and selected health outcomes. A gap in the existing literature demonstrates the need for research targeting children using longitudinal designs.

The purpose of our study was to evaluate the impact of an intensive education program designed for parents and pediatric patients with AE.

METHODS

Aims

This study aimed to measure outcomes of educational interventions including: (a) subjective and objective measures of the severity of eczema and (b) patient QOL. Of secondary interest was any impact on the family. The

intention of this study was not to change treatment regimes prescribed by the patient's physician.

Design of Study

The study was designed as a randomized controlled trial examining the impact of an educational intervention on QOL, family impact, and severity of pediatric AE. The sample comprised 61 pediatric patients diagnosed with AE and their parents. An exclusion criterion was severe eczema requiring treatment with systemic immunosuppressant therapy, for example, cyclosporin or tacrolimus. The participants, diagnosed with AE by their physician, were recruited by advertising in the local newspaper, audio/visual media coverage, and referrals from dermatologists and immunologists at the hospital where the study was conducted. A random number generator was used to place the participants into either the intervention group or control group.

Data Collection

At baseline, both groups of participants were assessed by using the clinical SCORAD assessment tool, to determine the severity of their eczema. (Mean severity grading of AE: mild < 15, moderate 15 < 40, severe > 40) In addition all participants were given QOL and DFI questionnaires (Table 1) to complete. The higher the score, the more QOL is impaired, and the greater the impact on the family.

The interventional group undertook the education program through a 2-hour workshop, together with their normal management regimen. The areas of education were: understanding AE, allergic and nonallergic trigger factors, investigations, basic skin care, topical corticosteroid therapy, infection, wet wraps, additional treatments, and complementary therapies. The education session also included a practical session on wet wrapping and cream application. Time for questions and sharing of ideas and experiences was provided.

The control group received the usual care including routine education, medical consultation, and management. At the week 4 and week 12 visits, both groups were assessed by using the clinical SCORAD assessment tool to determine the severity of their eczema, the QOL (either CDQOL or IDQOL depending on age of participant) and DFI questionnaires were repeated on both the control and the experimental groups. The education workshop was offered to the control group at the end of the study, as was explained to that group at the time of recruitment. Ethics approval was obtained from the institutional ethics committee.

Data Collection Tools

1. The Infants Dermatitis Quality of Life Index was filled out by the parents of children below 4 years of age. In this study it was used for children under 5 years of age because it related more appropriately to the age group. The IDQOL Index has shown good test-retest repeatability and sensitivity to change with treatment (12).
2. The Children's Dermatology Life Quality Index was used for children aged 5-16 years. Test-retesting of the tool on two separate occasions with 46 patients showed acceptable repeatability. However, the investigators suggest that further validation of the tool is required (13).
3. The Dermatitis Family Impact questionnaire was employed because there has been little information about the effect of childhood dermatitis on family function. The DFI provides a helpful guide to the management of AE. The 10-item questionnaire is user friendly, with good face validity (14).
4. The Scoring Atopic Dermatitis (SCORAD) was used to objectively evaluate the severity of patient's eczema. It has been widely used in clinical trials related to atopic dermatitis (18).

Data Analysis

Data were analyzed by using the Statistical Package for Social Sciences (SPSS) software (version 11). A sample size of 31 in each group was targeted to give 80% power to detect a difference in means of 3.50 (the difference between a Group 1 mean of 12.50 and a Group 2 mean of 9.00 for the CDQLI and IDQOL, assuming that the common standard deviation is 4.80 using a two-group *t*-test with a 0.05 two-sided significance level). A sample size of 12 per group is required to have a power of 80% to detect a difference in means of 15.00 for the SCORAD score (primary outcome measure). Analysis of covariances (ANCOVA) was performed to identify differences between the intervention group and the control group at each data collection time (baseline, week 4, week 12) for each outcome variable. An 0.05 level of significance was selected.

RESULTS

A total of 61 pediatric patients (0-16 years) from the metropolitan area of Adelaide diagnosed with AE were randomized to either the control group or the intervention group (29 participants in the control and 32 in the intervention group). Three participants were lost to

TABLE 1. Data Collection Tools: *Quality of Life Questionnaire*

CHILDRENS DERMATOLOGY LIFE QUALITY INDEX			
Hospital No:			
Name:	Diagnosis:	CDLQI	SCORE: <input type="text"/>
Age:	Date:		
The aim of this questionnaire is to measure how much your skin problem has affected you OVER THE LAST WEEK. Please tick ✓one box for each question.			
1.	Over the last week, how itchy “scratchy”, sore or painful has your skin been?	Very much Quite a lot	Only a little Not at all
2.	Over the last week, how embarrassed or self conscious, upset or sad have you been because of your skin?	Very much Quite a lot	Only a little Not at all
3.	Over the last week, how much has your skin affected your friendships ?	Very much Quite a lot	Only a little Not at all
4.	Over the last week, how much have you changed or worn different or special clothes/shoes because of your skin?	Very much Quite a lot	Only a little Not at all
5.	Over the last week, how much has your skin trouble affected going out, playing, or doing hobbies :	Very much Quite a lot	Only a little Not at all
6.	Over the last week, how much have you avoided swimming or other sports because of your skin trouble?	Very much Quite a lot	Only a little Not at all
7.	Last week, was it school time :	If school time: Over the last week has your skin affect your school work ?	Prevented school Quite a lot
	OR		
	Was it Holiday time :	If holiday time: How much over the last week, has your skin problem interfered with your enjoyment of the holiday ?	Very Much Quite a lot
8.	Over the last week, how much trouble have you had because of your skin with other people calling you names teasing, bullying, asking questions or avoiding you ?	Very Much Quite a lot	Only a little Not at all
9.	Over the last week, how much has your sleep been affected by your skin problem?	Very much Quite a lot	Only a little Not at all
10.	Over the last week, how much of a problem has the treatment for your skin been?	Very much Quite a lot	Only a little Not at all

Please check that you have answered every question. Thank you.

INFANTS DERMATITIS QUALITY OF LIFE INDEX (IDQOL)

Hospital No:			
Name:	Diagnosis:	IDQOL	
Age:	Date:	SCORE:	

The aim of this chart is to record how your child's eczema (dermatitis) has been. Each question concerns THE LAST WEEK ONLY.

Please answer every question.

Eczema severity

Over the last week how severe do you think your child's eczema has been? i.e. how red, scaly, inflamed or widespread?	Extremely severe Severe Average Fairly good None
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Life Quality Index

- | | | |
|---|--|---|
| 1. Over the last week, how much has your child been itching and scratching? | All the time
A Lot | A little
None |
| 2. Over the last week, what has your child's mood, been? | { Always crying
extremely difficult
Very fretful | Slightly Fretful
Happy |
| 3. Over the last week, approximately how much time on average has it taken to get your child off to sleep each night? | | More than 2 h
1 – 2 h
15 min to 1 h
0-15 min |
| 4. Over the last week, what was the total time that your child's sleep was disturbed on average each night? | | 5 h or more
3-4 h
1-2 h
less than 1 h |
| 5. Over the last week, has your child's eczema interfered with playing or swimming? | Very much
A lot | A Little
Not at all |
| 6. Over the last week, has your child's eczema interfered with your child taking part in or enjoying other family activities? | Very much
A lot | A little
Not at all |
| 7. Over the last week, have there been problems with your child at mealtimes because of the eczema? | Very much
A lot | A little
Not at all |
| 8. Over the last week, have there been problems with your child caused by the treatment? | Very much
A little | A lot
None |
| 9. Over the last week, has your child's eczema meant that dressing and undressing the child has been uncomfortable? | Very much
A little | A lot
None |
| 10. Over the last week, how much has your child having eczema been a problem at bath-time? | Very much
A little | A lot
None |

Please check that you have answered every question. Thank you.

DERMATITIS FAMILY IMPACT QUESTIONNAIRE (DFI)

Child's Name	Mother/Father/Carer	Date:	DFI
			SCORE: <input style="width: 80px; height: 25px; border: 1px solid black;" type="text"/>

The aim of this questionnaire is to measure how much your child's skin problem Has affected you and your family OVER THE LAST WEEK. Please tick one Box for each question.

- | | | | |
|-----|--|-----------------------|------------------------|
| 1. | Over the <u>last week</u> , how much effect has your child having eczema had on housework, e.g. washing, cleaning. | Very much
A lot | A little
Not at all |
| 2. | Over the <u>last week</u> , how much effect has your child having eczema had on food preparation and feeding. | Very much
A lot | A little
Not at all |
| 3. | Over the <u>last week</u> , how much effect has your child having eczema had on the sleep of others in the family. | Very much
A lot | A little
Not at all |
| 4. | Over the <u>last week</u> , how much effect has your child having eczema had on family leisure activities, eg swimming. | Very much
A lot | A little
Not at all |
| 5. | Over the <u>last week</u> , how much effect has your child having eczema had on time spent on shopping for the family. | Very much
A little | A lot
Not at all |
| 6. | Over the <u>last week</u> , how much effect has your child having eczema had on your expenditure eg costs related to treatment, clothes, etc | Very much
A lot | A little
Not at all |
| 7. | Over the <u>last week</u> , how much effect has your child having eczema had on causing tiredness or exhaustion in your child's parents/carers. | Very much
A lot | A little
Not at all |
| 8. | Over the <u>last week</u> , how much effect has your child having eczema had on causing emotional distress such as depression, frustration or guilt in your child's parents/carers. | Very much
A lot | A little
Not at all |
| 9. | Over the <u>last week</u> , how much effect has your child having eczema had on relationships between the main carer and partner or between the main carer and other children in the family. | Very much
A lot | A little
Not at all |
| 10. | Over the <u>last week</u> , how much effect has helping with your child's treatment had on the main carer's life. | Very much
A lot | A little
Not at all |

Please check that you have answered every question. Thank you.

follow-up at week 4 and week 12 (change of address and unable to contact them) but their data were included in the analysis at baseline and as missing values at week 4 and week 12. Demographic characteristics of subjects involved in the study are: 35 boys, 26 girls, mean age of 4.3 years, (4 months to 13 years).

Self-reported frequency of flares per month showed that 70.5% of children experienced more than three flares per month. Twenty-one (34%) of the children involved in the study used one steroid, and 16 (26.2%) children used two different topical corticosteroids, which consisted of hydrocortisone 1% for the face and betamethasone 0.02% for the body. Seventeen parents (27.9%) preferred not to use topical steroids on their children even when the eczema was moderate to severe.

An ANCOVA was conducted to compare the effectiveness of an educational intervention on severity of pediatric AE, QOL of child, and family impact. The covariate was the baseline scores (SCORAD, DFI, CDLQI, and IDQOL at week 1) and the dependent variable consisted of the above scores at week 4 and at week 12 after the educational intervention was administered to the intervention group. Preliminary checks were conducted to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes, and reliable measurement of the covariate.

Table 2 summarizes the results of the analysis of the outcome measures at baseline, week 4, and week 12 (Fig. 1).

SCORAD scores for both groups showed an improvement at week 4 and week 12. There was an improvement in mean of 22.46 (44.86%) at week 4 and 27.45 (53.85%) at week 12 in scores for the intervention group compared to 3.53 (7.39%) at week 4 and 7.52 (15.75%) at week 12 for the control group. SCORAD univariate analysis of variance revealed a level of significance at week 4 and week 12 of $p < 0.005$ for the group effect (Fig. 2).

Dermatitis family impact scores for both groups, total of 61 participants, showed a marginal improvement at

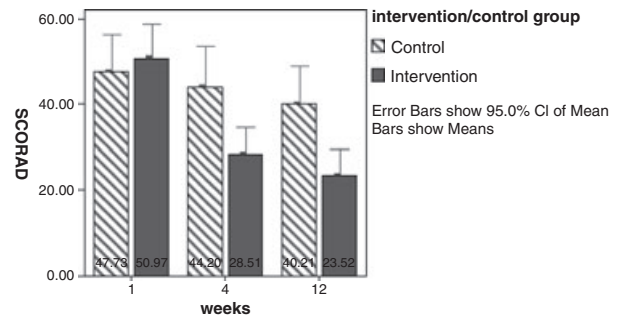


Figure 1. Comparison between intervention and control groups for Scoring Atopic Dermatitis (SCORAD).

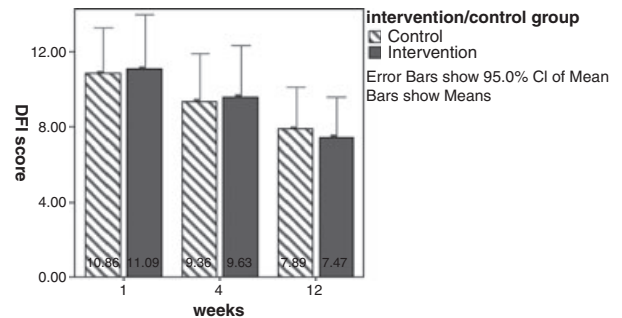


Figure 2. Comparison between intervention and control groups for Dermatitis Family Impact (DFI) scores.

week 4 and week 12, both for the control and intervention groups. There were no significant differences between the groups (Fig. 3).

Infant dermatology QOL scores for both groups, 38 participants total (62.3%), showed an improvement at week 4 and week 12. There was no significant difference between the groups (Fig. 4).

Childrens' dermatology life quality index scores for both groups, a total of 23 participants (37.7%), showed an improvement at week 4 and week 12. There was an improvement in mean of 2.35 (29.01%) at week 4 and 6.35 (78.39%) at week 12 in scores for the intervention group compared to 2.15 (22.18%) at week 4 and 2.61 (26.93%) at week 12 for the control group. Although the

TABLE 2. Comparison of Outcome Measures at Baseline and at Week 12

	Baseline		Week 4		Week 12	
	Control	Intervention	Control	Intervention	Control	Intervention
SCORAD	47.73 (22.61)	50.97 (21.83)	44.2 (24.75)	28.51 (16.61)	40.21 (22.9)	23.52 (16.53)
DFI	10.86 (6.47)	11.09 (8.02)	9.36 (6.56)	9.63 (7.27)	7.89 (5.85)	7.47 (5.79)
CDLQI	9.69 (5.09)	8.1 (2.99)	7.54 (4.22)	5.75 (4.17)	7.08 (4.52)	1.75 (1.16)
IDQOL	8.63 (4.32)	11 (8.29)	6.67 (3.56)	8.77 (7.04)	5.33 (3.02)	6.91 (5)

Values are expressed as mean (SD). SCORAD, Scoring Atopic Dermatitis; DFI, Dermatitis Family Impact; CDLQI, Children's Dermatology Life Quality Index; IDQOL, Infants' Dermatology Quality of Life Index.

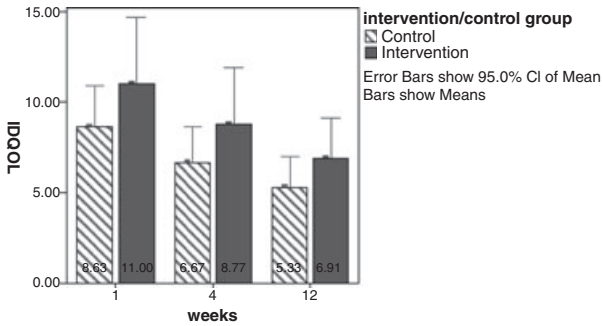


Figure 3. Comparison between intervention and control groups for Infants' Dermatology Quality of Life Index (IDQOL) scores.

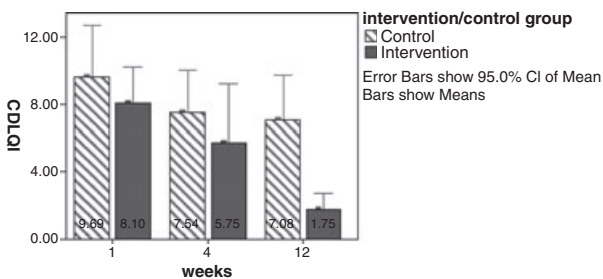


Figure 4. Comparison between intervention and control groups for Children's Dermatology Life Quality Index (CDLQI) scores.

between-group difference at week 4 was not statistically significant, at week 12 the group difference was significant at the level of $p = 0.004$. Anecdotal evidence suggests that the children were eager to be involved in the management of their eczema and became increasingly confident in managing their condition during the course of the study.

DISCUSSION

Consistent with previous research (4), our study demonstrated the conservative use of steroids in eczema management. Twenty-seven percent of parents involved in the study preferred not to use topical steroids on their children even when their eczema was severe, with 60.2% of children using one or two topical steroids. Previous research has shown that many parents fail to adhere to treatment regimens because of a fear of corticosteroids (19).

The difference in mean SCORAD scores at week 4 and week 12 was highly significant. There was an improvement in both groups, which could be due to the participants being involved in a study and seasonal factors. However, the intervention group showed a dramatic improvement. This finding supports the anecdotal

evidence from the Eczema Workshop at the Royal Children's Hospital in Melbourne. The improvement in the intervention group was achieved through education, without any changes to currently prescribed treatment. The researcher's role with the intervention group was to educate, support, and motivate parents and children in self-management. Of particular interest is the enthusiasm displayed by children aged 5–12 years, when in a group situation, who wanted to gain more information about eczema and take more responsibility for their treatment. Some parents and children required more motivation and support to implement improved compliance of basic skin care or to try wet wrapping.

Surprisingly, despite the SCORAD of the intervention group showing a significant improvement at week 4 and week 12, the DFI score showed no difference between the groups. Given the literature demonstrating a burden of care for families with children who have eczema (5–7), we expected that the intervention group would have an improvement in DFI scores consistent with improvement in SCORAD scores. A possible explanation for this study finding could be due to treatment compliance requiring more family time and effort and also the increasing financial burden in the management of their child's skin condition.

Similarly, the IDQOL showed no appreciable difference between the groups. A possible explanation for this finding could be parents filling out the questionnaires on behalf of the children or parents' perception that they require additional support beyond that provided in this study. There is some evidence to suggest that health related QOL measured by these methods may be poorly correlated with clinical severity (12).

The CDQOL scores for the intervention group showed a slight improvement at week 4 and a significant improvement at week 12 even though numbers in the study were small. This correlates with a sustained improvement in the SCORAD scores. We found that children aged 5–16 years learned in a different way from parents/caregivers who were responsible for care and management of an infant's eczema. Data from field notes suggest that some children in this age group needed further motivation and negotiation in order to practice self-management. Study findings are consistent with research that has shown that patients can effectively self-manage their illness if provided with the necessary skills (8,20). Further research is warranted to explore self-management education strategies and outcomes in pediatric populations. Study data thus far have concentrated on adult populations (16).

We found that parents believed there were allergic components to their child's eczema and were subsequently restricting diets. During the workshop allergic and non-

allergic trigger factors were discussed and parents were encouraged to further investigate allergies by consulting with allergists and dietitians before restricting diets. This supports the collaborative professional approach to dealing with a multifactorial chronic condition (8).

However, we found that the time available in normal consultation was insufficient to cover all aspects of the education package designed for the study. Educational strategies used in this study could be incorporated into community-based workshops targeting parents and children with eczema.

This longitudinal study was conducted over 3 months and goes some way toward describing the impact of education interventions. However, consistent with previous research (12) the long-term impact of education intervention was not evaluated. It would be interesting to see whether a similar trial could achieve improvement in SCORAD scores at 12 months. Data were collected from only one hospital site and therefore do not provide an opportunity for comparison between hospitals.

CONCLUSION

Education and support are vital to increasing patients' ability to self-manage their condition and treatment. Key findings demonstrated that education decreases the severity of eczema regardless of the prescribed treatments. QOL measures did not significantly improve with decreased severity of eczema. Further research is needed to determine the most effective approaches to improve the QOL of both pediatric eczema patients and their families.

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