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Parental self-efficacy and the management of childhood atopic eczema: development and testing of a new clinical outcome measure

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What is already known about this topic?

- Effective child eczema management requires systematic parental education.
- Parental self-efficacy in eczema care is a factor influencing the effectiveness of parental eczema care, yet there are no measures of it.

What this study adds

- PASECI is a valid, reliable and sensitive measure.
- PASECI is useful scale to evaluate the effectiveness of eczema education interventions.

Abstract

Background: Effective parental management of childhood eczema requires education and support to reduce disease severity and improve child quality of life. Self-efficacy is a key factor influencing effective chronic disease management. There are no published scales to measure parental self-efficacy in managing childhood eczema. The Parental Self-Efficacy with Eczema Care Index (PASECI) was designed to measure parental self-

efficacy in managing childhood eczema as a pre- and post-intervention tool in the evaluation of a structured Eczema Education Programme (EEP).

Objective: To develop and test the validity, reliability and sensitivity of a new outcome measure (PASECI) designed to assess parental self-efficacy in managing their child's eczema to determine pre and post changes in educational intervention evaluation studies.

Methods: PASECI was developed from literature, expert consultation and piloting of a 40-item prototype. The final 29-item scale is arranged on 4 subscales. Parents of children with eczema aged 0-16 years (n=242) attending the EEP were assessed at 1 week pre-EEP and 4 weeks post-intervention. Cronbach α and factor analyses were undertaken.

Results: PASECI has face, content and construct validity. It is reliable, with high item internal consistency (Cronbach $\alpha > 0.87$ in all domains). Factor analysis revealed 4 viable domains. It was sensitive to change for post intervention measures using Sign tests ($p < 0.001$).

Conclusions: PASECI is a useful, valid, reliable and sensitive evaluative outcome measure of self-efficacy in parents managing childhood eczema.

Key words: Education, childhood eczema, atopic eczema, parental management, self-efficacy, outcome measure, self-management

Introduction

Atopic eczema (AE) affects up to 20% of children in developed countries¹. The quality of life impact of eczema can be high for both children and their families². Effective parental management minimises disease

severity and improves child and family quality of life³. This requires a degree of knowledge, skill and confidence from the parent; confidence is akin to the psychological concept of self-efficacy. Self-efficacy (SE) is a concept derived from Bandura's Social Learning Theory that refers to an individual's belief in their own capacity to positively affect their health behaviour^{4,5}. Reviews^{6,7,8} and policy⁹ highlight the value of SE in effective self-management of chronic disease. However, a gap in the literature is evident since little attention has been given to its application within a dermatological context and the self-efficacy of carers, although there are exceptions¹⁰. A systematic review of educational interventions for child eczema has revealed both a lack of theoretical underpinnings and methodological limitations¹¹. The development of an outcome measure of parental self-efficacy in eczema care provides a basis for evaluating interventions directed towards enhancing parental confidence in managing their child's condition. This study set out to develop and then validate a tool to measure parental self-efficacy and test the feasibility of its clinical application through a wider study evaluating an Eczema Education Programme directed at supporting parents' in managing their child's eczema^{12,13}.

A recent systematic review¹¹ found no controlled studies evaluating self-efficacy outcomes in the parental management of eczema to date. With the exception of a range of severity measures¹⁴ the most frequently used outcome tools applied to evaluate clinical and research interventions for childhood AE, measure dermatology specific child¹⁵ and infant¹⁶ quality of life and family impact². These child and family outcome tools measure quality of life impact but do not give an indication of the educational support needs of parents managing child eczema. Accurate assessment of parental education and support needs is a critical factor in ensuring that interventions are directed toward increasing the self-efficacy required to enable parents to manage their child's AE as effectively as possible.

'The General Self-Efficacy Scale (GSES) has been developed¹⁷ and validated^{18,19} with large scale populations. It is useful for assessing an individual's belief in how they can be self-efficacious. However, the items within the GSES lack specificity to clinical contexts²⁰, such as childhood eczema. A disease or domain-specific

measure of perceived self- efficacy is likely to be more useful than a general measure as they will reveal specific deficits that will enable targeted and personalised support by the healthcare professional ^{20, 21}.

Examples of disease-specific parental self-efficacy scales include studies of parents of children with asthma²², preterm neonates²³, children with chronic pain²⁴ and with minor child illness²⁵. Robust tool development continues on scales to measure self-efficacy to manage chronic disease²⁶.

The Parental Self-Efficacy with Eczema Care Index (PASECI) was developed as an outcome measure for a study investigating the feasibility and impact of a structured education programme, termed the Eczema Education Programme (EEP)¹², which was designed for parents of children with eczema. Through the initial phase of delivery of the EEP we planned to develop and validate this scale ¹³. The EEP service offered parents access to standardised, evidence-based eczema education delivered in both specialist centres and the community¹². The EEP sample provided the basis for the validation of the PASECI scale.

Objective

To develop and test the validity, reliability and sensitivity of a new outcome measure designed to assess parental self-efficacy in managing their child's eczema and for use as a self-report outcome measure to determine pre and post changes in eczema educational intervention studies.

Materials and Methods

Development and testing of the Index (PASECI)

The design of PASECI was informed by Bandura's theory of SE⁵, guidance on construction of SE scales^{20, 21}, and a review of published research studies that had employed a self-efficacy measurement scale^{4, 22,23,24,25, 26}. A literature review was used to enhance content and construct validity. Existing self-efficacy scales from clinical areas outside the dermatology field were reviewed for relevant questions, content and wording that was suitable for application to the context of parental management of child eczema management. From this review, a set of 40 questions relevant to the disease-specific aspects of personal efficacy in eczema care were developed and grouped into four theoretical domains. Face and content validity was achieved by circulating successive iterations of the scale with the EEP expert steering group until the 40 item prototype (V7) scale was produced (see Appendix [Figure 1](#)); this version was tested. Each item could be scored on an 11 point scale (0 = not confident to 10 = very confident) to increase the response options and ability to distinguish between smaller differences on the scale, as well as to avoid heaping at the mid-point, as can be found on five point scales²⁰. A total range of scores with the index is 0-400. The PASECI index provides a basis for measuring changes in parental efficacy with eczema care over time. The 4 domains or sections of the prototype index, each with 9-11 questions are:

1. *Managing Medication*: Q1-10 (10 questions)
2. *Managing eczema and symptoms*: Q 11-19 (9 questions).
3. *Communicating with Health Care Professionals*: Q20-29 (10 questions)
4. *Managing Personal Challenges when caring for a child with eczema*: Q30-40
(11 questions)

Prior to commencement NHS Research Ethics and Research Governance approvals were secured for this service evaluation study.

Participants and sampling: We sought to recruit as many parents as possible from the 356 who attended the EEP programme over a 19 month period. A purposive or non-probability sample (n=242) (described below) was obtained from the full set of EEP study respondents who completed the baseline questionnaire; these were representative of the parents attending the EEP. As this was a new tool, we were unable to estimate an effect size and so undertake a power estimate. The inclusion criteria were the same as for the entry to the EEP, that is, 1) parent of child (0-16) with an eczema diagnosis; 2) family understanding the English language; and 3) child attending host hospital services or lived in, or had a GP in the local primary care community.

The PASECI questionnaire was completed by the parents one week before attending the educational intervention (EEP) and 4 weeks post-intervention to enable measurement of any change in parental self-efficacy. The modal sub-group were parents of infants (0-4 years), who constituted 88% of this sample. The study location was a large inner city UK metropolitan borough characterised by high levels of mobility, ethnic diversity and social deprivation.

Statistical methods: The Statistical Package for the Social Sciences (SPSS version 20) and the programming language 'R' (version 3.0.0) were used for the analyses to determine statistically the validity and reliability of the scale and the number of factors or domains that were being measured. Analysis was organised into five main stages:-

- i) Descriptive statistics were run on the 40 items of the PASECI. We examined the distribution of items (questions) or variables; allowing investigation of missing data, spread and the operation of any floor or ceiling effects.
- ii) Item (question) by item analysis of change was used to investigate any variable change before and after the EEP using Sign tests for the 40 pre-post-tests, as the data were of an ordinal nature. A 0.1% Bonferroni significance level was used to address the issue of multiple significance testing.
- iii) Factor analysis was used to verify appropriateness of domains or sections within the index. This was applied to the *pre*-intervention data using the Principal Components Method, followed by Varimax

rotation. Following the results of the first stage of analysis, 6 items (questions) with substantial proportions of missing data were excluded (10%). Only 34 of the 40 items were included in the initial factor analyses. After the initial results, a further reduction to 29 items was made, fixing the number of factors extracted at four. As a further check on the consistency of the factor solution, the Maximum Likelihood and Principal Axes Methods of factor extraction were applied to the list of 29 items. Following factor analysis we transferred two items to new domains in the *prototype* scale, producing the *final scale*; this produced a scale with a reduced number of questions, within each of the four domains of the index.

- iv) Reliability analysis involved examining the internal consistency of items; this was undertaken on the final scale using the Cronbach alpha statistic.
- v) Correlations were used to investigate the relationship of parental self-efficacy to both child eczema severity and their quality of life. We wanted to test the hypothesis that improvements in parental self-management and therefore more effective adherence to an optimal management regimen may be related to improved child outcomes. For cases pertaining to 0-4 year old (infants) only, Pearson correlations were calculated between these four domain total scores of the PASECI and the Patient Orientated Eczema Measure (POEM)²⁷, Infant Dermatitis Quality of Life (IDQOL) Index¹⁶.

Results

The following results derive from the five stages of analysis within the validation process and as such are presented in corresponding sequence. This data relates to the 242 parental cases, who were representative of the sample of parents attending the EEP¹². The *actual* sample size for each element of the analysis varied because of missing item data and the smaller number of available cases after education was delivered.

(i) *Descriptive statistics*: Across all questions in our original prototype index of 40 items, the median scores ranged from 5-9, with lower quartiles ranging from 2-6 and upper quartiles from 8-10 (the maximum possible item rating). The mode was the maximum possible rating of 10 for over half of the items. However,

there was no floor or ceiling effects so all items were useful for discriminating between participants. Six items had missing data for at least 25 (10%) out of 242 cases: these related to the child's engagement in their care, which would be more limited for infants (questions (Q) 12, 13, 14, 16), telling the nurse when you disagree with them (Q26) and the impact of feeling under pressure from work (Q31) due to the possibility of not being in paid work.

ii) Scale's sensitivity to change: After controlling for multiple testing by setting a significance level of 0.1%, a significant improvement ($p < 0.001$) was found for all 40 items (number analysed ranged from $n=93$ to 130). The pre-intervention responses for some items were skewed towards the top end of the scales and so little improvement was possible. These results indicate that the PASECI is sensitive to change.

iii) Factor analysis and structure of the scale: From the initial factor analysis of 34 items, extracting all factors with eigenvalues >1 produced 5 factors. However, as the fifth eigenvalue only marginally exceeded 1, we concluded that a four-factor solution (an index of four domains) is a good representation of the PASECI items. The pairwise correlation matrix of items revealed strong correlations between items within, with all exceeding 0.75, ('Managing medication' domain (Q8-10) and the 'Communicating with health professionals' domain Q21-24 and Q28-29). This led to further examination of face validity, suggesting that those items differentiating health professionals might be redundant. The final 29 item questionnaire has removed items containing the terms 'nurse' or 'doctor or GP' and amended the language to refer to the generic term 'health professional'. The four factor model loadings for the reduced set of 29 items are presented (see Table 1); those <0.4 were omitted. In summary, the factor analysis revealed that the four factor or domain structure of the index or scale was appropriate and viable, there was scope to reduce the number of items (questions) to 29 and there was no need to have questions differentiating between different health professionals. A review of items following factor analysis highlighted opportunities to move some items to more appropriate domains. The final 29-item scale is given in Figure 1.

iv) Reliability (internal consistency) of scale items: Cronbach's alphas for the final 29 item scale with two transferred items are 0.906, 0.874, 0.915 and 0.953 for the respective domains; 'Managing medication', 'Managing eczema and symptoms', 'Communicating with health care professionals' and 'Managing personal challenges' domain. These are all very good correlations that indicated high levels of internal consistency between the items or questions. In no cases were significant increases obtained by removal of items from a domain.

v) Correlations of parental self-efficacy and other outcome measures child outcomes: Table 2 presents sample correlations and confidence intervals between the total scores over items within each of the four PASECI domains in the final 29 item scale and the POEM (patient orientated severity measure) and IDQOL (infant quality of life) scale totals to explore if changes in parental self-efficacy may vary with the child outcomes, -eczema symptom severity and quality of life respectively}. As Q12, 13, 14 and 16 were removed from the original 40-item PASECI and are potentially relevant to older children, only cases pertaining to children aged 0-4 were included in this analysis. All correlations in Table 2 are very weak and so the relationship of the PASECI domain scores with a common measure of eczema severity and quality of life has not yet been established.

Discussion

The PASECI scale has face, content and construct validity and reliability (internal consistency). In the final 29-item scale, the rigour and usability of the tool was improved by removing items not relevant to infants (the modal group) and collapsed to unifying responses to questions relating to engaging with health professionals, rather than differentiating the type, due to indications that the factor structure would be the same. The data indicates that the PASECI is sensitive to change. During the testing period linked to the EEP evaluation quantitative data was collected alongside qualitative from focus groups on parental self-efficacy with eczema care. Focus group (qualitative) data from parents' post-intervention, showed clear themes, revealing enhancement of self-efficacy, when PASECI was used as an outcome measure, strengthening the indications of validity¹³. This combination of data (triangulation) was used to enhance the validity of the tool. Factor analysis clearly revealed that items in three domains or sections of the index held up giving a factor structure of three factors 'Managing Eczema and Symptoms', 'Communicating with Health Care Professionals' and 'Managing Personal Challenge's and indicated sufficient viability to retain the fourth (remaining) domain, 'Managing Medication'.

The relationship of parental self-efficacy to the child clinical outcomes, quality of life and disease severity, has not yet been established. This is surprising given that efficacious eczema management by parents should increase the probability of improvements in child clinical outcomes and therefore we believe this hypothesis warrants further testing.

The only similar and theoretically relevant outcome measure reported in dermatology was a German self-efficacy scale (SEND) for parents of pre-school children with AE²⁹. The validity of SEND questionnaire's 9 items were informed by theoretical concepts and parental interviews. It is claimed to be valid and reliable; however, the scale was not published in the paper and thus it is difficult to adequately appraise. Also, its use in English language countries is not established. Hence the PASECI tool addresses a gap in the literature on self-efficacy scales applied to the dermatology field. Specifically, it provides an effective method to assess

parental education needs and to evaluate the impact of interventions designed to promote effective management of their child's eczema.

Analysis of some items from the prototype 40-item PASECI V7 was undertaken by Mitchell and Fraser.³⁰

They sought to develop a suite of valid and reliable research instruments to appraise parents' self-efficacy for performing AE management tasks, outcome expectations of such tasks, and self-reported task performance in a community sample of parents of children with AE. The validity and reliability of PASECI was additionally confirmed in Mitchell and Fraser's analysis, however, their analysis excluded the domain 'Managing personal challenges' and as such this process was incomplete³⁰.

We had considered the scope to include an item on steroid phobia, as a factor affecting the confidence of parent's in managing treatment effectively, and therefore the achievement of suitable adherence, however, we decided not to do so as the reliability analysis highlighted that the questions on confidence in correctly using steroids and successfully using moisturisers remain, and as separate items within the scale.

The scale validation process has some limitations. Despite the demonstrable strengths in validity and reliability, further investigation of inter-relationship between PASECI and DFI scores, and clinical severity is required to more fully test its relationship to other commonly used and potentially related measures of quality of life and clinical severity. One possible explanation for the low correlation reported from our wider study previously¹¹ is that disease severity was not a criterion for access to EEP and the quality of life impact we reported at baseline was low-moderate. Another explanation may be linked to the observation that many of the newly diagnosed infants did not have severe eczema; this is documented in our EEP evaluation paper (p633)^{13 & 27}. Another limitation is that there is reliance on self-reported data, which may affect the fidelity of the results. The generalizability of the findings is potentially confined to a UK metropolitan population, although validity of 25 of the main scale items has been established within an Australian study³⁰. Although the PASECI can be effectively used to measure changes in parental self-

efficacy with eczema care, further developmental work is required on the categorisation of high and low PASECI score bandings to enhance the index's utility.

The PASECI is of value as an outcome measure in studies designed to test the effectiveness of structured education or other interventions to improve parents' management of their child's eczema¹³. It also has the potential to provide a more accurate view of the efficacy of educational interventions directed towards parents of children with eczema. The final PASECI could be usefully applied by clinicians as an assessment and evaluation scale in the dermatology setting. By obtaining a baseline measure of parental self-efficacy to manage their child's AE, they could target parents more likely to respond to self-efficacy focused interventions, such as parental teaching about medications, to those with low self-efficacy baseline scores. With the drive to harmonise the assessment of the clinical signs of eczema and derive a core set of outcomes³¹, there is scope to consider the effective measurement of a wider range of key psychological factors that have bearing on the efficacy of eczema management, especially in explanatory trials. Self-efficacy may be considered as an intermediate outcome measure that has bearing on clinical outcomes.

A recent and comprehensive review of self-efficacy interventions⁸ and a robust study²⁶ by the same group highlights the significant potential of self-efficacy based programmes to improve the quality of life of patients with chronic diseases. We contend that the recommendations made are of equal relevance to parents of children with chronic skin diseases, such as eczema, as they have a key role in their effective management. Accurate measurement of parental self-efficacy and the evaluation of self-efficacy based interventions are of high importance in the promotion of effective management of childhood chronic dermatoses. Assessment of parental self-efficacy with eczema care provides a basis for enhancing concomitant educational support to the use of existing therapy that requires self-management.

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MANAGING PERSONAL CHALLENGES WHEN CARING FOR YOUR CHILD WITH ECZEMA:***How confident do you feel that you can manage your child's eczema in these situations?***

20. When I am feeling tired.
21. During or after experiencing personal or family problems.
22. When I am feeling low or anxious.
23. When I am feeling ill.
24. Without support from my family or friends.
25. During a holiday.
26. When I have too much housework/childcare to do at home
27. When I have other time commitments
28. When it's difficult to get the prescribed creams
29. When it's difficult to get the right clothes for my child

Table 1: Factor loadings after Varimax rotation with a forced four factor solution for the 29 item Parental Self-Efficacy with Eczema Care Index (PASECI) (n=208) from children aged 0-16 years who took part in the Eczema Education Programme, London 2009-11 (*nb: the numbers are not consecutive but reflect those drawn from the original 40 item prototype*)

Item	Factor 1	Factor 2	Factor 3	Factor 4
<i>Managing medication</i>				
1. Choose a moisturiser (grease) that is suitable for your child			.413	.534
2. Successfully apply moisturisers (grease) to your child's eczema				.740
3. Successfully apply antibiotic creams to your child's eczema				.789
4. Correctly use steroid creams for your child				.793
5. Make the right choice of medication if the symptoms of your child's eczema become worse			.593	.565
6. Know what to do if you think your child's eczema has become infected			.605	
7. Judge whether the treatments/medication for your child's eczema works				.577
8. Ask a GP if you want to change your child's medications		.579		.407
<i>Managing eczema and symptoms</i>				
11. Manage your child's scratching behaviour so as to stop further skin damage			.732	
15. Manage to avoid things that irritate/aggravate your child's eczema			.569	
17. Control your child's eczema so that he/she can play like other children			.556	

18.	Manage your child's eczema so that his/her symptoms are under control	.683			
19.	Reduce any sleep disturbance brought about by your child's eczema	.604			
<i>Communicating with health care professionals</i>					
20.	Get access to a health care professional if you need to speak to them about your child's eczema	.607			
21.	Tell the GP when your child's eczema is not getting better	.783			
23.	Ask the GP to explain things when you don't understand	.760			
25.	Tell the GP when you disagree with him/her	.709			
27.	Decide when to call in help from the GP or nurse	.728			
28.	Ask to see a specialist doctor	.695			
<i>Managing personal challenges when caring for your child with eczema</i>					
30.	When I am feeling tired	.792			
32.	During or after experiencing personal or family problems	.810			
33.	When I am feeling low or anxious	.828			
34.	When I am feeling ill	.805			
35.	Without support from my family or friends	.729			
36.	During a holiday	.682			
37.	When I have too much housework/childcare to do at home	.809			
38.	When I have other time commitments	.760			
39.	When it's difficult to get the prescribed creams	.589	.441		
40.	When it's difficult to get the right clothes for my child	.581			
<i>Initial eigenvalue</i>		14.927	2.271	1.538	1.257

<i>Percentage of variance explained</i>	51.471	7.830	5.303	4.333
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Table 2: Pearson correlations, 95% confidence intervals and sample sizes showing the correlation between the Infant Dermatitis Quality of Life (IDQOL) index and Patient Orientated Eczema Measure (POEM) and the four domains of the Parental Self-Efficacy with Eczema Care Index (PASECI) ¹ on the final 29 item scale, from children aged 0-4 years who took part in the Eczema Education Programme, London 2009-11

	Managing Medication	Managing Symptoms	Communication	Personal Challenges
IDQOL ²	-.146 (-.280,-.007) (n=198)	-.114 (-.247,.024) (n=204)	-.110 (-.243,.026) (n=207)	-.212 (-.342,-.073) (n=195)
POEM ²	-.030 (-.258,.202) (n=73)	-.092 (-.312,.137) (n=75)	-.115 (-.332,.113) (n=76)	-.151 (-.373,.087) (n=70)

1. The higher PASECI score the greater the parental self-efficacy

2. The higher the quality of life score the worse the qol impact (IDQOL) or disease severity (POEM)

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