

## ORIGINAL ARTICLE

# Improved management of childhood atopic dermatitis after individually tailored nurse consultations: A pilot study

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## Keywords

atopic dermatitis; care; consultation; nurse; parents

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## Abstract

**Background:** For optimal therapy of atopic dermatitis (AD) in children, parent education for treatment strategies that consider the episodic course and multiple triggers is essential. Regular consultations with doctors often cannot appropriately provide this. Therefore, supplemental patient education tools have been established. We evaluate single nurse consultations, assessing their global benefit, parents' self-confidence, and children's symptoms and sleep disturbance.

**Methods:** Parents of children with AD were invited for an individually tailored nurse consultation by the doctor initially consulted in cases where difficulties in implementing care recommendations were detected and established therapeutic patient education (TPE) group programmes were impracticable. Parents' estimation of their own self-confidence, current disease severity and its treatment was assessed by a questionnaire at the consultation and by telephone 14 days later.

**Results:** Parents of 1628 children (mean age 1.7 yr) attended consultations in 22 centres (317-6 patients; median 38). At follow-up parents indicated a significantly increased self-confidence to handle the recommendations and >90% rated the consultation highly supportive. The frequency of severe symptoms was significantly lower (20% of initial cases), as of moderate symptoms (50%). Median scores for sleep disruption and pruritus decreased by >50%.

**Conclusions:** Individually tailored single nurse consultations for AD are associated with a significant benefit for the families after 14 days. We recommend these in addition to the usual medical care in cases where participation in TPE programmes is impossible or a short-time follow-up is required. To substantiate their effect, studies with a long-term follow-up and a control group are warranted.

Atopic dermatitis (AD) is a chronic disease with a prevalence of up to 20% in children (1), and it negatively affects the quality of life (QOL) of patients and their families (1-4). 'Patient empowerment' recently has gained attention as a strategy to qualify patients for a self-responsible handling of their chronic disease (5). For optimal treatment of AD, the episodic aggravation due to multiple triggers has to be considered and strategies adapted accordingly. This requires

from patients a clear knowledge of its aetiology, of diagnostic approaches, and of the multiple treatment recommendations. Visits, even to specialized doctors, often do not offer the capacity to provide this in appropriate depth (6). Consequently, for AD, a few centres worldwide have worked on therapeutic patient education (TPE) programmes to raise self-management skills, treatment efficacy and QOL (3, 7-15).

Various methods of TPE for AD have been studied: individual sessions (7, 12) or education in groups (3, 9, 10, 13, 14, 16) and single (7-9, 14) or multiple sessions (3, 10, 13, 14, 16). Approaches have involved nurses (7, 9, 16-18) or trained psychologists (10) vs. interdisciplinary teams (3, 12, 13).

## Abbreviations

AD, atopic dermatitis; QOL, quality of life; TI, telephone interview; TPE, therapeutic patient education.

Additional tools, such as videos (10, 19) or an e-health portal (15), have been studied as well.

The parameters most frequently investigated are improvement of skin symptoms and of QOL. A recent Cochrane review (20) demonstrated significant results in favour of TPE programmes for childhood AD concerning skin symptoms in five effective (8–10, 13, 14) vs. two negative trials (11, 12), but conflicting results for QOL parameters (7, 8, 13, 14). However, the largest studies have shown significant improvement also of QOL (13).

Few studies have investigated single nurse-led consultations either for adult patients (17) or for parents of affected children (7, 9, 11, 18). Most have demonstrated improvement of skin symptoms (9, 11, 18) and of QOL (11, 17). The direct comparison of a nurse visit to one of a dermatologist revealed comparable effects on symptoms and QOL, but a higher level of satisfaction with the nurse consultant, who had spent twice as much time (11).

In Germany, a multisession interdisciplinary TPE programme of six workshops for a group of 6–8 families was established in the late 1990s, funded by the National Ministry of Health (13, 21, 22). Most medical insurance companies pay for the expenses. However, some patients cannot be reached by such programmes for various reasons (23).

We therefore evaluated a single nurse consultation for families not able to participate in a TPE programme within a reasonable time. The outcome parameters had a special focus on the parental-rated global assessment and on the improvement of sleep, both of which have not been studied so far in TPE programmes, as well as on the parental self-confidence and the skin symptoms of the child.

## Methods

Patients and parents were initially seen by a specialized paediatrician, dermatologist or allergologist in a hospital's medical clinic or in a private practice. If deficits in treatment or difficulties with the implementation of recommendations were identified, further education was suggested. In case, the family was unable to participate in the established TPE programme (i.e. no offer in the living area, language difficulties and educationally disadvantaged populations), they were invited for a nurse consultation.

The registration for the regional specialized nurse was performed by the doctor after parents' consent. All trainers were experienced nurses or medical assistants certified as 'atopic dermatitis trainers' of the Arbeitsgemeinschaft Neurodermitisschulung e.V. (Working Committee of Atopic Dermatitis Therapeutic Patient Education).

## Evaluation of AD and its management in the families

In a structured interview at the beginning of the nurse consultation, parents' estimation of the current severity of their child's AD using a validated patient reported outcome measure ('skin detective' (22), related to the SCORAD Score (24)), the therapeutic recommendations and therapy applied, as well as parents' self-confidence, was assessed. For the questionnaire relate to Tables 1 and 2 and Fig. 3.

After 14 days (min–max: 10–20), patients were contacted by the nurse for a structured telephone interview (TI), during which relevant questions from the questionnaire (symptoms, self-confidence) were repeated to assess the current situation, and three items of a global assessment were included (for details refer to Results).

## Individualized care consultations

The consultations took place at the institution initially visited and were restricted to approximately 30 (–45) min within 4–8 wk after registration. All patients had received individual treatment plans from their doctor. These were the basis for the consultation, and the medical recommendations were not altered. Following the identification of the respective needs in the family by the questionnaire, the instructions focused on the transfer of care recommendations and practical skills into families' daily lives and on reinforcing their knowledge. Parents could choose topics for more detailed instructions (emollients/basic therapy; cleaning of skin; techniques of topical application of care products; advice on bathing; use of topical wraps; avoidance of aggravating triggers; alternatives to scratching; transfer of recommendations into daily life). The instructions followed the established specifications of the German Working Committee of Atopic Dermatitis TPE for the nurse lessons of the TPE programme (25) and were reconfirmed in a pre-study meeting of the involved nurses.

## Institutional review board

The project was submitted to the local institutional review board of the Charité, Medical Faculty of the Humboldt University Berlin. Due to the nature of the intervention, it was not considered a medical study and a formal process was not initiated. The principles outlined in the Declaration of Helsinki were followed.

## Statistics

Data management, data cleaning and statistical evaluation were carried out using the SAS system (version 9.3; SAS Institute Inc., Cary, NC, USA). All children with at least a baseline questionnaire were included in the analysis. Differences between the before and after parent-reported skin symptoms and parental self-confidence were tested with the sign test. Pruritus and sleeplessness scores before and after intervention were compared using a *t*-test. The significance level was set at 0.05.

## Results

Parents of 1628 children with AD [mean age 1.7 yr (25/75th Percentile 0.7/4.0); female 42.9% (n = 699)] received single nurse consultations. The consultations were performed by 25 persons in 22 centres between 11/2011 and 09/2013.

These families were not participating in established, grouped, multisession TPE for the following reasons (n = 1628, multiple answers possible): (i) TPE was not offered

**Table 1** Parental assessment of their confidence with different topics of atopic dermatitis care at the care instruction and 2 wk later

Question	Always	Pre-dominantly	Rarely	Never
Confidence in choosing the adequate care strategy, N (%)				
Pre	104 (6.4)	628 (38.6)	757 (46.5)	133 (8.2)
Post	414 (25.5)	1070 (65.8)	97 (6.0)	7 (0.4)
Confidence in choosing the best care or therapeutic product, N (%)				
Pre	62 (3.8)	480 (29.5)	907 (55.7)	172 (10.6)
Post	447 (27.5)	1010 (62.1)	114 (7.0)	16 (1.0)
Confidence in nutritional topics, N (%)				
Pre	478 (29.4)	589 (36.2)	360 (22.1)	109 (6.7)
Post	615 (37.8)	631 (38.8)	221 (13.6)	26 (1.6)
Confidence and calmness/ease in strenuous situations, N (%)				
Pre	181 (11.1)	587 (36.1)	578 (35.5)	263 (16.2)
Post	388 (23.9)	974 (59.9)	169 (10.4)	40 (2.5)

Missings summarized for the two time points of analysis (of n = 1628): pre (median, min–max) 13, 6–92; post: (median, min–max) 48, 39–134.

**Table 2** Parental assessment of the current severity of their child's atopic dermatitis at the care instruction and 2 wk later

	None	Little	Moderate	Severe
Dryness of skin, N (%)				
Pre	156 (9.6)	557 (34.2)	667 (41.0)	224 (15.0)
Post	441 (27.1)	800 (49.1)	314 (19.3)	43 (2.6)
Redness of skin, N (%)				
Pre	75 (4.6)	427 (26.2)	767 (47.1)	355 (21.8)
Post	333 (20.5)	858 (52.7)	344 (21.1)	63 (3.9)
Knotty thickness, N (%)				
Pre	637 (39.1)	461 (28.3)	366 (22.5)	154 (9.5)
Post	1034 (63.5)	415 (25.5)	124 (7.6)	21 (1.3)
Small vesicles, N (%)				
Pre	673 (41.3)	506 (31.1)	321 (19.7)	122 (7.5)
Post	1070 (66.7)	394 (24.2)	113 (6.9)	17 (1.0)
Oozing/crusts, N (%)				
Pre	247 (15.2)	2638 (39.2)	555 (34.1)	177 (10.9)
Post	644 (39.6)	662 (40.7)	244 (15.0)	46 (2.8)
Scratch marks, N (%)				
Pre	993 (61.0)	384 (23.6)	185 (11.4)	59 (3.6)
Post	1135 (69.7)	348 (21.4)	98 (6.0)	15 (0.9)

Missings summarized for the two time points of analysis (of n = 1628): pre (median, min–max) 6.5, 4.0–11.0; post: (median, min–max) 32.0, 30.0–34.0.

in the region of approximately 20 km (13.3%, n = 217), (ii) caretaking for their children was too difficult to organize (10.7%, n = 174), (iii) travelling to the TPE location seemed too far (5.3%, n = 86), (iv), the overall expense of participation was too high (1.7%, n = 27) and (v) other reasons (40.7%, n = 662).

A questionnaire assessed parents' transfer of the recommendations from the attended doctor. Table 1 depicts the parental assessment of their self-confidence concerning different topics at the time of the individualized care consultation and 2 wk

later. In Fig. 1, the individual changes over time are shown ( $p < 0.01$  each). The extent of the changes relates to the possible category of answers (always–predominantly–rarely–never).

In Table 2, the parents' view of the severity of skin symptoms at the respective time point is shown as are individual switchovers between the categories (always–predominantly–rarely–never or none–little–moderate–severe) from the day of the consultation to the TI (Fig. 2,  $p < 0.01$  each, *sign test*). Parental assessment of the severity of their child's current pruritus and sleeplessness before the consultation and 2 wk later is demonstrated in Fig. 3.

The overall rating of parents of their benefit from the individualized care consultation 2 wk after the instruction was very positive. Of all parents, 92.1% (n = 1499/1587) answered the question 'I can transfer the recommendations better into daily life' with 'yes'. In addition, 95.6% (n = 1557/1586) considered the individualized instruction with the child to be very important, and 95.7% (n = 1558/1582) would recommend the individualized instruction to others.

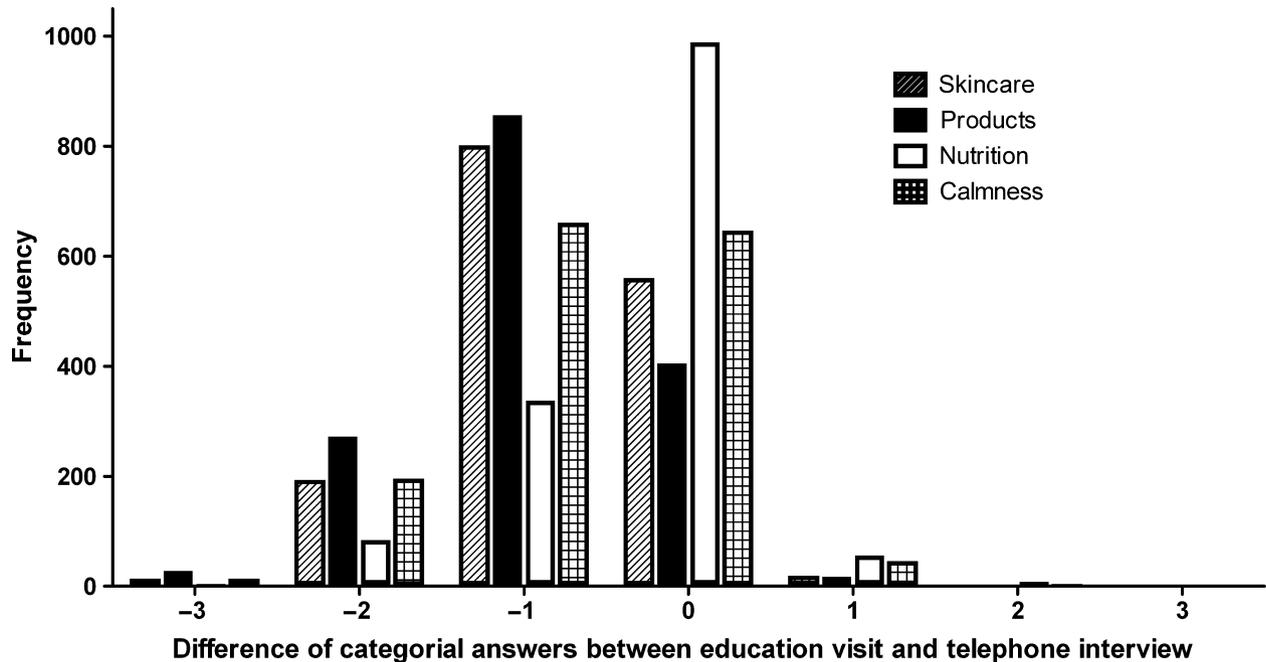
## Discussion

Parents of  $\geq 1600$  children with AD attending a single individually tailored nurse consultation of treatment recommendations from a previous face-to-face contact with a doctor reported significant improvement after 2 wk concerning all main end-points: the global assessment of the visit was ranked very high by the parents, their confidence to handle the various topics of their child's AD increased, and their rating of the children's current skin symptoms, pruritus and sleep improved significantly.

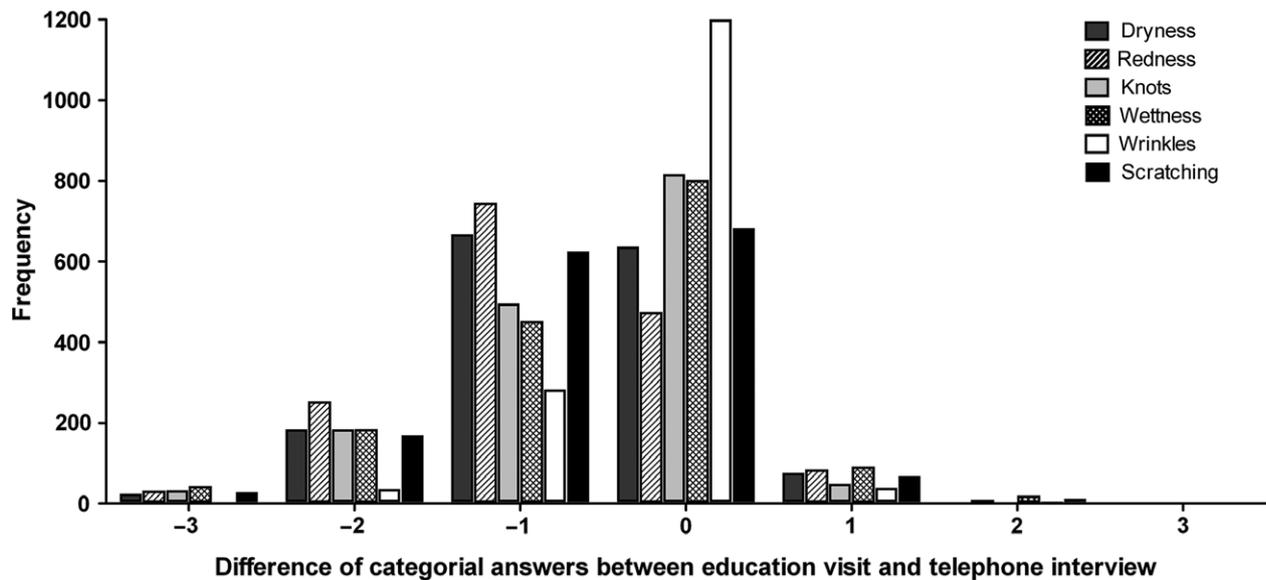
None of the randomised controlled studies to date have assessed the participants' global assessment of their benefit from the respective intervention (20). We were able to show that a single consultation of a skilled nurse was rated highly supportive by the parents with 92–96% (three items) indicating a clear overall benefit of being able to transfer the recommendations better into daily life. Therefore, we disagree with the idea that single interventions are not sufficient to improve control of the child's eczema or to change parents' behaviour (7).

As opposed to the established TPE programme, we intended to provide a low-threshold measure for parents to participate in the nurse consultation and likewise for the institutions to offer it. Therefore, we decided to accept some limitations for its design. We did not collect data on the indication relevant for the doctor to recommend the consultation nor on the number of refusals, to keep the bureaucratic effort low. However, nurse sessions took place  $\geq 4$  wk after the medical consultation to minimize confounding due to prior treatment changes.

We selected a short re-assessment period of 2 wk to gain a high percentage of responses. Other studies investigating outcome parameters at different time points have shown an initial improvement, mostly at 4 wk. TPE studies with longer follow-up periods show stable effects within a 12-month period (15, 18). However, we cannot exclude later deteriorations concerning our outcome parameters.



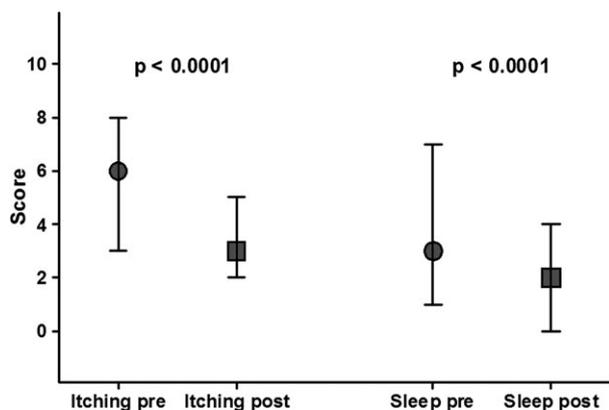
**Figure 1** Relative changes of the individual parental answers to a questionnaire (four items, four categories each) concerning their self-confidence in handling the care recommendations from the time point of the care instruction compared to the telephone interview 2 wk later (pre n = 1628, post n = 1603). The changes are significant for each topic (p < 0.01, sign test).



**Figure 2** Relative changes of the individual parental answers to a questionnaire (six items, four categories each) concerning their child's current atopic dermatitis skin symptoms using the 'skin detective' (22) from the time point of the care instruction compared to the telephone interview 2 wk later (pre n = 1624, post n = 1598). The changes are significant for each skin symptom (p < 0.01, sign test).

Two weeks after the consultation, the vast majority of parents (approximately 90%) felt predominantly or always confident in choosing the adequate care strategy or product, in

contrast to 45% or 33% before (Table 1). Further, >80% rated their confidence to handle strenuous situations predominantly or always with calmness or ease in contrast to <50% before



**Figure 3** Parents' assessment of the severity of their child's pruritus and sleeplessness at the care instruction and during the telephone interview 2 wk later [scale 0–10; median (25–75th Percentile); pre: n = 1625, post: n = 1600; p < 0.01, t-test].

(Table 1). The fact that the rating of nutritional topics did not change in contrast to the other items (Fig. 1) reflects the specificity of the skin care consultation.

A significant proportion of the parents indicated an improvement of skin symptoms (Fig. 2), mostly less dryness, redness and excoriations. The frequency of a parental rating of severe symptoms was reduced to approximately 20% and of moderate symptoms to 50% (Table 2). This is in agreement with other investigations of nurse consultations (9, 11, 18); however, the data are difficult to compare, as the extent of changes depends on the initial severity of AD and on the tool assessing it. We did not measure the objective SCORAD, but a parental estimation derived from it. Other studies have found a reduction of SCORAD scores between 75% and 38% for the nurse-educated group vs. 50–26% of the standard treatment (9, 11, 18). The multisession TPE programme led to a reduction of 38–46% in the intervention groups of different ages vs. 13–30% without intervention (13). Although we did not measure the consumption of care products, the improvement is most probably caused by a more appropriate use of the treatment products, which was also found in a previous nurse-led intervention group (18) as well as a TPE programme (3).

In childhood AD, sleep disturbances due to scratching are a highly relevant problem for the patient himself, but also for the caring persons. Night-time waking of the child requires parental help, leading to frustration, exhaustion, anxiety and depression in many families, in which even siblings lose sleep (26). A strong correlation exists between the severity of the child's eczema and the sleep disturbances of the mother (27). Reid and Lewis-Jones (28) found an average of 2–7 periods of waking per night and an average parental sleep loss of 2.6 h per night. Therefore, diminishing the sleep disruption is a relevant improvement for the families. The single consultation of a nurse in our study was related to a significant reduction of the median scores for pruritus and sleep disruptions in the children by 50% (Fig. 3).

Previous studies of AD education programmes have not separately analysed improvement of sleep (20), only implicitly analysed by the SCORAD (11, 18). Sleep disruption has been measured in a video-based education programme with a reduction of 67% in contrast to 20% by standard dermatologist treatment (10), which is comparable to our data. AD support groups have led to a significantly better rating of children's QOL, including the item sleep (14). A significant reduction of pruritus has been found in two other nurse-led interventions (14, 18), in the latter study to an extent comparable to our findings (18). We did not assess QOL parameters; however, a correlation of severity of eczema with QOL scores of children and families has been demonstrated by others (7). Further, it has been shown that the severity of itch correlates to patients' QOL (29).

Presumably one benefit of a nurse consultation is the more appropriate time length for parents to understand relevant topics. Two authors have indicated approximately twice the time of standard visits (9, 11). It remains an open question whether the personal contact with the nurse is another key to the impact of the education. Our nurses were all experienced trainers, and we consider this a relevant factor.

The consultations were offered to parents not participating in the established TPE programme due to various reasons (driving distances, caretaking of the child/children, overall costs). The demand for additional forms of patient education besides multisession TPE programmes is obvious, and various ways of education seem feasible. Other easy-to-access education forms, such as video education at home (10) or an e-health portal (15), have a significant effect on symptom control and/or QOL measurements. Further studies should focus on the respective target groups. For a large number of families, however, the nurse consultation in the living area was a highly appreciated measure with respect to improvement of self-confidence concerning the daily measures. Effects on the long-term course have to be evaluated in further studies.

### Conclusion

Parents of ≥1600 children with AD reported significant improvement in all main end-points after a single individually tailored nurse consultation in addition to an initial doctors' contact. The global assessment of the visit was highly valued by the parents. They indicated an increase in their confidence to handle the various topics of their child's AD, and a significant reduction of their children's skin symptoms, pruritus and sleep.

Individual nurse consultations seem to be an effective low-level intervention for those families who are not able to attend the comprehensive TPE programmes, as well as for those where the need for additional help is identified. Hypothetically, single nurse consultation vs. multisession TPE programmes as two types of patient education refer to different target groups. To substantiate the efficacy of single nurse consultations and to identify patient characteristics with relation to the most effective type of education programme (10, 15), studies with a longer follow-up and with relating control groups would be desirable.

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