

# Therapeutic Patient Education in Children with Atopic Dermatitis: Position Paper on Objectives and Recommendations

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**Abstract:** Poor adherence is frequent in patients with atopic dermatitis (AD), leading to therapeutic failure. Therapeutic patient education (TPE) helps patients with chronic disease to acquire or maintain the skills they need to manage their chronic disease. After a review of the literature, a group of multispecialty physicians, nurses, psychologists, and patients worked together during two international workshops to develop common recommendations for TPE in AD. These recommendations were structured as answers to nine frequently asked questions about TPE in AD: What is TPE and what are its underlying principles? Why use TPE in the management of AD? Who should benefit from TPE in AD? How can TPE be organized for AD? What is the assessment process for TPE in AD? What is the evidence of the benefit of TPE in AD? Who are the people involved in TPE? How should TPE be funded in dermatology? What are the limits of the TPE process?

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Atopic dermatitis (AD) is the most common chronic inflammatory skin disease in children and is characterized by pruritic flare-ups alternating with periods of remission (1). Effective treatments are available (2), but to be effective, they need to be utilized regularly (3). Because of the significant effect of chronic disease on the quality of life (QoL) of patients and parents (4) and the relative complexity of the treatment, poor adherence is frequent, leading to therapeutic failure (5). Therapeutic patient education (TPE), a new approach in the treatment of AD, is aimed at improving the therapeutic adherence of patients and their families.

According to the World Health Organization (WHO) definition, TPE helps patients with chronic disease to acquire or maintain the skills they need to manage their life in the best possible way. TPE is already in use in the treatment of many chronic diseases (e.g., asthma, diabetes, cardiovascular disease) (6).

There are many examples of therapeutic patient education approaches applied to the treatment of AD (7,8), but in the literature, these activities differ in terms of their type, content, organization, timescale, and evaluation methods (9).

Official recommendations for TPE for asthma and diabetes have been published (10). Recommendations are also needed for AD (11), and health authority agencies (e.g., the U.S. Food and Drug Administration [FDA] and European Medicines Agency [EMA]) have asked for formalized and harmonized educational actions evaluated in randomized multicenter studies.

The aim of this article is to propose common recommendations for therapeutic education for patients with AD and their parents. After an exhaustive review of the literature, an international group of multispecialty doctors, nurses, psychologists, and patients worked together to develop common recommendations for TPE in AD. The recommendations were a consensus from experts integrating cultural differences among the different countries involved. These recommendations were structured as answers to frequently asked questions, designed in a way useful for practitioners. This work was finalized during the two international therapeutic education workshops organized by the Foundation for Atopic Dermatitis, Pierre Fabre Laboratory, Toulouse, France, 2010, and Rome, Italy, 2011.

#### **WHAT IS TPE AND WHAT ARE THE UNDERLYING PRINCIPLES?**

According to the WHO definition (12), TPE helps patients acquire and maintain the skills they need to

manage life with a chronic disease. TPE is a component of therapeutic management. TPE results in a transfer of skills to patients or parents and should not be confused with simple information or advice; information in the waiting room is a useful but insufficient condition for TPE (6). TPE is a patient-centered process consisting of organized activities, including psychosocial support, hospital organization and procedures, and health- and disease-related behaviors. It helps patients and their families understand and manage the disease and its treatment together to maintain or improve QoL.

TPE includes patient preferences and shared decision making. In an exchange with the patient and parents, the caregiver integrates their experience into the care process (13). This experience includes the patient's and parent's knowledge, beliefs, motivations, and failures and the effect of the familial, social, and professional context (14).

#### **WHY USE TPE IN THE MANAGEMENT OF AD?**

In AD, TPE should be integrated into the care process because topical treatment regimens are often complex, and patients and their families are directly responsible for applying and adapting them to the daily condition of the disease. Therefore patients need to acquire the skills necessary to self-assess and adapt local treatments for the long-term control of the disease. In AD, TPE is expected to improve a patient's therapeutic adherence, general health, and QoL.

#### **WHO SHOULD BENEFIT FROM TPE IN AD?**

In theory, TPE should be offered to all patients and families with AD, regardless of the patient's age or the type, condition, or progression of their disease. In practice, however, education programs are mainly targeted toward patients with severe disease, lower QoL, and/or lack of therapeutic adherence, sometimes resulting in cessation of treatment.

TPE should be offered to patients and parents with a history of therapeutic failures, with or without efficient and credible treatment, and to families who feel they have poor social support (15). There is no evidence to establish the age at which TPE directed toward children instead of parents can have benefits. In practice, TPE programs are usually targeted toward parents of children under 8 years and toward children themselves from 12 to 18 years. Education programs can be proposed but never imposed, and should always be adapted to the sociocultural situation of the patient.

## HOW CAN TPE BE ORGANIZED FOR AD?

The TPE approach can be organized on a one-to-one basis (16–18) or in groups (19–21). The two approaches are not mutually exclusive; both group and individual sessions may be utilized.

### How is the Initial Visit Organized?

The initial step of TPE is informing the patient and family of the concept, and receiving consent (Table 1). After the patient and parents agree to TPE, participation in a personalized initial session, a collective workshop, or an information meeting (lecture) can be proposed.

A doctor and nurse team can conduct the initial personalized visit in a hospital setting or in a private practice setting during a 30-minute to 1-hour visit. In a private practice setting, it may be possible to complete this initial consultation in less time (but no less than 15 minutes) by focusing on the main educational points: severity of the disease, effect on daily life, treatment, and adherence barriers (topical steroid phobia, forgetfulness, lack of time, complexity and cost of treatment) (22). The content of this initial visit can also be spread over several sessions.

A guideline document (Table 2) can also help the doctor–nurse team assess the resources and difficulties of the patient and parents. After listening to the patient’s and parents’ experiences, complaints, fears, knowledge, and motivations, the most important obstacles to treatment adherence and the patient’s resources are identified. At this point, “educational objectives” (skills to be acquired) can be established with the patient (Table 3). These objectives are tailored to the age of the patient and can be defined in terms of “To be capable of...” For example:

To be capable of adapting my treatment (including topical corticosteroids and emollients) to the condition of my skin.

To be capable of applying my treatment without help.

To be capable of managing my itch or pain.

To be capable of following the prescription (including corticosteroids).

To be capable of recognizing a complication (herpes, bacterial infection).

To be capable of detecting a flare-up.

When caregivers assess the patient and parents for “steroid phobia,” they should investigate using open questions such as, “What do you think about your treatments?” This type of indirect questioning may avoid creating a defensive reaction in patients due to guilt. Then, to teach those skills, the caregiver should propose a personalized program of TPE that can include different educational resources (patient-centered communication techniques, educational methods, tools; Table 4). A personal written action plan (WAP) helps the patient and parents reduce the gap between the prescription and the application, reminds them of the therapeutic objectives, and helps them to better adhere to the treatment (23). A systematic short-term appointment or a follow-up (hotline, mail, nurse’s assistant) is included in the WAP.

After this initial personalized visit, further visits can be organized with the nurse or assistant, focusing on, for example, applying local treatments, detecting flare-ups, discussing prevention.

### How are Collective Sessions Organized?

Collective sessions can be organized in two ways (Table 5), as lectures or workshops.

**TABLE 2.** *Guide for Initial Visit Before Establishing Educative Contract in Patients with Atopic Dermatitis*

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- Tell me about the history of your disease.
  - What’s the cause of your disease, in your opinion?
  - What factors worsen or improve your disease?
  - What’s the aspect of your disease that bothers you the most?
  - What is your treatment? Do you have any concerns about your treatment?
  - How is the treatment going? Describe in detail what you do.
  - Are there things that you cannot do because of your disease?
  - How is the relationship with your family, friends, and work colleagues?
  - What do you do when you feel you need help? Whom do you turn to?
  - What are you expecting from this meeting or visit?
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**TABLE 1.** *Guide to Presenting Therapeutic Patient Education (TPE) to Patients*

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Propose a personalized education approach that addresses the patient’s specific problems (e.g., adherence, steroid phobia).  
 Explain the goals and benefits of TPE to the patient, presenting testimonies of former patients (film, audio, or video).  
 Indicate where and when the sessions will take place.  
 Give patients an explanatory leaflet and allow them enough time to ask questions and decide whether they want to accept, refuse, or postpone TPE.  
 Establish the patient’s consent.

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**TABLE 3.** *Skills to be Acquired During Educational Personalized Visit or Workshops*

Knowledge of the disease	Disease mechanisms, treatment mechanisms, aggravating factors
Practical skills	Applying treatment and adapting it to disease severity, self-assessing disease severity
Relational skills	Explaining the disease to others, knowing whom to turn to during a flare-up and when to ask for help

**TABLE 4.** *Educational Resources for Learning Skills*

Resources	Examples
Patient-centered communication techniques	Active listening, empathy, encouragement, and interview to enhance the patient's motivation (especially during educational diagnosis and follow-up to induce a change in behavior and provide support)
Educational methods	Interactive presentations, case studies, round tables, brain-storming, simulations (analysis of situations or patient diaries), practical work, workshops, simulations of procedures, role-playing, documentary accounts, motivational interviews
Tools	Written action plans, posters, picture books, video (doctor-patient interviews), widgets, reminders, CD-ROMs, booklets, drawings of objects of everyday life

**TABLE 5.** *Collective Therapeutic Education*

Lecture	Workshop
One or two sessions, 30 minutes to 1.5 hours	One to three sessions, 30 minutes to 1.5 hours
Advantages	Groups of 10 participants
Capacity to reach a large audience	Advantages
May lead to individual consultations	Allows patients to exchange personal experience (peer to peer)
Mixes all age groups	Allows experts to address practical skills (demonstrations) and specific situations (role-playing)
Disadvantages	Allows for use of interactive tools
Impersonal information	Disadvantages
Acquisition of technical skills is not addressed	Need to sort groups according to age
Impossible to consider individual beliefs and behavior	

Lectures may be open to a large group composed of children, parents, or adult patients. After these lectures, individual sessions may be organized according to the patient's and parents' needs or the caregiver's discretion.

Thematic collective workshops may be organized in small groups, sorted according to age. A two-person team (expert and group leader) including doctors (dermatologist, allergologist, pediatrician), psychologists, and nurses, runs these workshops. Each workshop lasts approximately 2 hours, and within this time an interactive exchange is established based on a chosen theme. Peer-to-peer exchange enriches the communication between caregiver and patient and parents.

#### WHAT IS THE ASSESSMENT PROCESS FOR TPE IN AD?

Assessment is an indispensable aspect of the education process, but TPE is a complex intervention "made up of various interconnecting parts" (24). Therefore assessment of TPE has to include a biomedical outcome, QoL scores, and specific psychological scores.

Three main elements can be included in the assessment process.

#### Assessing the Patient

This assessment concerns children and parents and may be conducted at the beginning of the education process, at the end of the program, and 6 to 12 months after the end of the program.

The doctor can measure the severity of the disease using a medical score (e.g., SCORing Atopic Dermatitis [SCORAD], Eczema Area and Severity Index [EASI]), or the patient can do so using a self-assessment score [Patient-Oriented SCORAD (25), Self-Administered EASI (26)]. Self-assessment scores enable the patient and the doctor to follow the development of the disease between sessions and is thus a factor in evaluating therapeutic adherence. These tools are available to download online.

The systematic use of a QoL score enables the patient or parent to communicate the effect of the disease on daily life and enables the doctor to assess the severity of the disease.

Patient and parent adherence is more difficult to assess but can be assessed by patient diaries or questionnaires. Adherence may also be monitored electronically in clinical trials (27).

Steroid phobia and other concerns and misbeliefs should be detected (28). Seventy percent of parents of children with AD admit to applying significantly less local corticosteroid than prescribed (29). Assessing steroid phobia can be useful to address this problem, which affects therapeutic adherence. The origins of patients' fears and their effects on behavior (28) can be explored. The discussions that the caregiver can then put forward become more pertinent because they are based on the fears of the patients and enable the caregiver to personalize the discourse and better convince the patient of the benefits of adhering to the treatment.

It is important to assess the patient's and parents' knowledge of the disease. This is generally carried out using a simple questionnaire.

### **Evaluating the Program Content**

Patient and parent satisfaction questionnaires are established, and the patient and the education team fill them in at the end of each workshop.

### **Evaluating the Medicoeconomic Impact**

The effect of TPE can also be assessed by measuring the number of days of hospitalization, work productivity, and treatments costs.

## **WHAT IS THE EVIDENCE OF THE BENEFIT OF TPE IN AD?**

TPE has been shown to have a positive effect when utilized for chronic diseases such as asthma, diabetes, and cardiovascular disease, improving QoL scores and reducing severity scores and serious complications (30,31). In AD, education programs for children and their parents have a positive effect on QoL and disease severity (7,8). Eight randomized controlled trials (RCTs) describing TPE programs in children with AD or their parents have been published (15–19,32–34). TPE appeared to be effective in improving QoL in four of seven of these RCTs (one study did not assess QoL) and disease severity in four of eight, but comparison of the studies is difficult because the content of the educational programs is heterogeneous and varies greatly between studies. For example, Staab's intervention (19) comprised once-weekly 2-hour sessions led by a multidisciplinary trained team over a 6-week period, whereas Shaw's intervention

(18) comprised a single 15-minute session led by a trained medical student. In the three studies in which no significant effect of TPE on QoL was found, the duration of educational intervention was <30 minutes. There is a lack of data about which severity group and age group could benefit most from TPE. In the Staab study, the authors randomized 992 children ages 3 months to 12 years (with their parents), and adolescents with moderate to severe AD (SCORAD > 20) to group sessions of standardized intervention programs once a week for 6 weeks or no education (control group). They reported statistically more significant improvements over a 12-month period in the QoL and the disease severity in all three of the age groups than the control group (SCORAD: 3 mos–7 yrs,  $-17.5$ , 95% confidence interval [CI] =  $-19.6$  to  $-15.3$  vs  $-12.2$ , 95% CI =  $-14.3$  to  $-10.1$ ; 8–12 yrs,  $-16.0$ , 95% CI =  $-20.0$  to  $-12.0$  vs  $-7.8$ , 95% CI =  $-11.4$  to  $-4.3$ ; 13–18 yrs,  $-19.7$ , 95% CI =  $-23.7$  to  $-15.7$  vs  $-5.2$ , 95% CI =  $-10.5$  to  $0.1$ ). Parents of affected children younger than 7 years old experienced significantly better improvement in all five QoL subscales, whereas parents of affected children ages 8 to 12 years experienced significantly better improvement in three of five QoL subscales. Further studies are needed to compare different educational programs in terms of the effect on QoL and severity of disease, durability of effect, cost-effectiveness, suitability in dermatologic practice, and optimal target population. Nevertheless, as a complex intervention, TPE may work best if tailored to local circumstances rather than being completely standardized (24).

## **WHO ARE THE PEOPLE INVOLVED IN TPE?**

TPE always involves health professionals, but the speciality profiles can vary (nurses, psychologists, doctors, dieticians). Trained dermatology nurse intervention may be helpful (35). Recently Schuttelaar et al (36,37) showed that the level of care provided by a nurse practitioner in terms of improvement in disease severity and QoL outcomes was comparable with that provided by a dermatologist and that this intervention was cost saving and cost effective. In addition, the parents were more satisfied with the care that a nurse practitioner provided, although the educational teams should be multidisciplinary and multiprofessional. Team members should be trained in the pedagogy of TPE and be knowledgeable about the disease. Whether a doctor or a nurse runs the education sessions, the message must be the same across the range of interventions. A coherent message is essential for the patient and parents.

### **CAN TPE BE PROVIDED IN PRIVATE PRACTICE?**

The needs of the patient in terms of medical care necessarily generally involves the participation of nonhospital practitioners (pediatrician, allergologist, general practitioner) in educative actions. Private practitioners can play an active part in TPE by discerning which patients may benefit from intensive education and referring them to an eczema center or “atopic school.”

Many eczema centers in hospital settings include private practitioners who also apply the principles of TPE in their private practice. The time needed for education sessions can be dissuasive, but under certain conditions, quality TPE can be provided in private practice.

Cooperation between the education team and the patient’s doctors is essential to avoid discordant messages, often the root cause of false beliefs or inappropriate behavior and poor treatment adherence. The sharing of education tools (WAP) and evaluation scores (POSCORAD, SAEASI, patient-oriented eczema measure) is encouraged (38).

Integrating TPE into the initial and continuous medical education of doctors involved with children could contribute significantly to improving the quality of health care. Some tools can improve the exchange of information between the patient, the doctor, and the education team; the telephone or e-mail can be used to follow up educative actions (39). The Internet can be integrated into the educative structure, providing accessible, validated, illustrated, and attractive information for patients (40). The Web can offer interaction and peer-to-peer exchange (e.g., social networks). This tool is useful for helping patients and parents adhere to education programs, favoring information exchange through blogs or promoting the activities proposed by the eczema center.

Posting easily accessible self-assessment scores (POSCORAD) on the Web ([www.opened-dermatology.com](http://www.opened-dermatology.com)) reinforces and facilitates communication between the patient and the education team. Assessing the severity of the disease between using a self-assessment score helps patients and parents adapt treatment and helps doctors respond better to patient demands.

### **HOW SHOULD TPE BE FUNDED IN DERMATOLOGY?**

In dermatology, TPE is an emerging and thus precarious activity. Even though the various health authorities (FDA, EMEA, WHO) encourage the

large-scale development of eczema centers, a lack of financial assistance limits this development.

Funds for setting up education programs can come from different sources. In Germany and France, health agencies provide funds for officially recognized education structures that have a regular activity. In the United States, funds are raised through patient and family donations. Pharmaceutical companies sometimes help fund the organization of specific workshops, staff training, and the production of education tools through foundations or donations.

### **HOW TO SET UP AN ECZEMA CENTER OR ATOPIC SCHOOL**

There are several steps before integrating an education program into a hospital department. The first step is to propose a formal project that outlines the objectives of the program, the target population, the practical organization, which personnel will be involved, and the type of evaluation to be used. This project must be integrated into the global strategy of the institution. Cooperation with education teams in other departments and specialties encourages the sharing of investments and the exchange of best practices and facilitates the setting up of a new structure.

Promotion or participation in clinical trials reinforces the assessment process of the structure, which encourages exchanges between eczema centers and atopic schools and leads to an improved care process.

### **WHAT ARE THE LIMITS OF THE TPE PROCESS?**

Patients and parents may refuse TPE. Caregivers should analyze patient and parent receptiveness to TPE before any TPE process is initiated. TPE constraints (availability, schedule) should be clearly explained to patients and parents with practical examples before any decisions are made.

TPE is a “holistic” process that should not be separated from therapeutic management, but TPE programs should not begin before an AD flare-up is correctly treated.

TPE is time consuming, not only in private practice, but also in a hospital setting. The need for trained caregivers, the costs of training and the time needed to organize and administer programs are limitations. In certain circumstances, the cost:benefit ratio could be unfavorable to TPE.

Common barriers to adherence include poor literacy, learning difficulties, social difficulties, cultural background, limited access to health care, high cost of

treatments, psychiatric illness, or emotional problems (41). For these reasons, TPE programs should always be individually tailored to patients' educational and cultural backgrounds.

### CONCLUSION

TPE integrates the management of severe chronic dermatitis, especially AD. Its objective is to increase patient and parent autonomy in adapting treatment to the course of their disease and to live optimally with their condition. High-quality TPE should be patient centered, evidence based, deeply integrated in AD treatment, taught by multidisciplinary trained caregivers, well defined (activities and content) and scheduled (group or individualized sessions), and include an individual assessment of the effect of the TPE program.

### ACKNOWLEDGMENTS

Dr. S. Barbarot and J. F. Stalder thank Alan Ball for reviewing the manuscript and editorial assistance. The Foundation for Atopic Dermatitis, Pierre Fabre Laboratory, sponsored two international workshops on TPE in AD (Toulouse, France, 2010; Rome, Italy, 2011). The Foundation for Atopic Dermatitis played no role in the writing of this article.

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