

Therapeutic patient education in atopic eczema

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Summary

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Therapeutic patient education (TPE) is a patient-centred process that entails the transfer of skills (e.g. self-management, treatment adaptation) from a trained healthcare professional to patients and/or their carers. TPE has been shown to help improve adherence, prevent complications, and improve quality of life (QoL) in chronic illnesses such as diabetes, asthma and cardiovascular disease. Recently, TPE recommendations for patients with atopic eczema have been proposed. TPE is a four-step process: understanding the patient's knowledge, beliefs and hopes; setting age-appropriate educational objectives; helping the patient (or carer) to acquire skills; and assessing the success of the programme. TPE programmes always involve a multidisciplinary team of healthcare professionals, including nurses, psychologists, doctors and dieticians who are expert in the disease area. TPE should be offered to (never forced upon) any patient who has experienced treatment failure, or to families who feel they lack social support. High-quality TPE programmes should be evidence-based, tailored to a patient's individual educational and cultural background (rather than being standardized in form and content), and have well-defined content and activities.

Issues involving patient education are some of the more dominant factors influencing patient satisfaction.¹ The World Health Organization states that therapeutic patient education (TPE) can help patients who have chronic diseases to gain skills required that will help them improve their everyday life.² TPE has been shown to contribute effectively in preventing complications and improving quality of life (QoL) and treatment adherence for numerous chronic illnesses, including diabetes, asthma and cardiovascular disease.³ The aim of TPE is not simply to provide information or advice, such as that found in the waiting room, but entails the transfer of skills (e.g. self-management, treatment adaptation) from a trained caregiver to the patient or their parents.³ TPE is a patient-centric process (Fig. 1)⁴ that covers organized activities such as psychosocial support, hospital and procedural organization, and health- and disease-related behaviours. It allows patients and their families to better understand their disease and cope with treatment together, in order to maintain or even improve QoL and treatment adherence.² Unlike educational programmes for other pathologies, the development of TPE in the field of dermatology remains poor.

Treatment adherence is low in chronic disease (50% of prescribed treatment is actually used by patients) and even lower in chronic skin disease.^{5,6} Adherence to treatment is a key issue in atopic dermatitis (AD), and an unsuccessful AD treatment can often be linked directly to poor treatment adherence and even the complete cessation of therapy. Treatments that

are effective need to be used regularly.^{7,8} But local treatments can be complex and require the patient and their family to gain the relevant skills to self-assess and adapt local treatments to control their disease in the long term. Unfortunately, parents and/or patients often have numerous beliefs and worries regarding topical anti-inflammatory treatments.⁹

There are many examples where TPE has been used in treating AD.^{10–13} Although recent educational structures called 'eczema centres' or 'atopic schools' have been developed by a number of hospital teams around the world, these programmes differ by process, content, organization, schedules and evaluation.¹³ Recommendations for TPE have already been published for asthma and diabetes¹⁴ and the evaluation of formalized and harmonized educational actions in randomized, multicentre studies has been requested by health authority agencies. Recently, common recommendations for TPE for patients with AD and their parents have been proposed.²

Recent developments

Developing therapeutic patient education for atopic dermatitis

TPE is a four-step process (Fig. 2).¹⁵ The first step is aimed at understanding what the patient already knows, believes, fears and hopes for, in order to determine the patient's difficulties and resources. During this first step, barriers to adherence

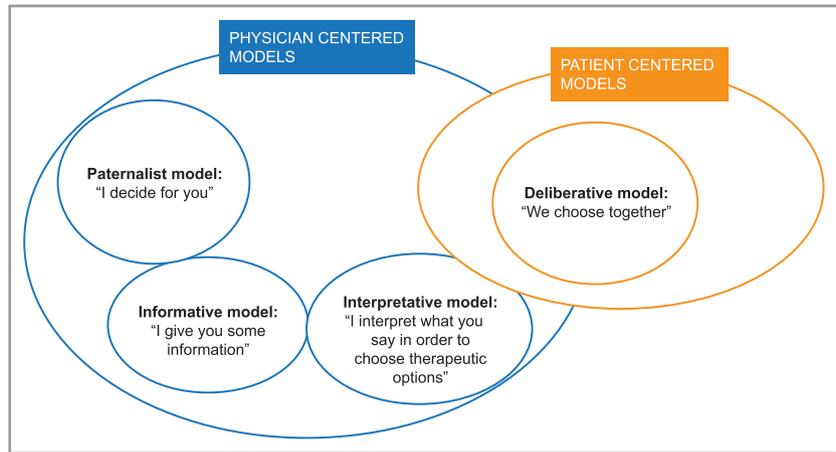


Fig 1. Four models of the physician–patient relationship. Adapted from Emanuel, Emanuel.⁴

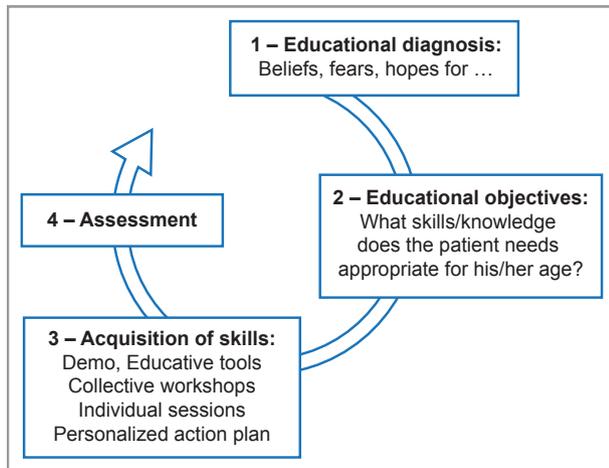


Fig 2. Therapeutic patient education: a four-step process. Adapted from Gagnayre.¹⁵

Table 1 The skills acquired during an educational personalized visit or workshop

	Objectives
Knowledge of the disease	Disease mechanisms, how the treatments work, 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 in a flare-up, or when to ask for help, etc.

(e.g. phobia of topical steroids, forgetfulness, time restraints, complexity or cost of treatment)¹⁶ should be identified. Specific tools measuring self-care ability and the educational and support needs of the patient may also be helpful.¹⁷

In the second step, educational objectives (i.e. the required skills) can be determined with the patient, based on their age (Table 1). At this stage, it is important to establish which skills the patient needs in order to better manage their disease, according to their difficulties and resources.

The third step is about acquisition of skills by the patient or their parents. During this step, health providers can use a number of different educational resources (e.g. patient-centred communication techniques, practical demonstrations and educational tools) (Table 2). The development of a personal written action plan with the patient or carers can help them to adapt their treatment, act as a reminder of the therapeutic objectives, and promote better adherence to the treatment.¹⁸ The written action plan could also include a short-term appointment or follow-up plan, which can be carried out by hotline, mail, or by an assistant nurse. This step can be organized on an individual basis or in a group.² A recent world-

wide study showed that individual sessions have been developed in half the centres, particularly in Italy and France.¹³ Individual sessions can be useful in allowing health-care providers to establish an overall patient profile in order to customize the TPE programme. Individual sessions are usually led by two experts (i.e. a physician and a nurse), but they can also be run by a nurse alone.^{19,20} Collective group sessions may be lectures or small workshops (Table 3). Lectures are designed for a large public body formed of child and adult patients, as well as parents. Individual sessions can then be organized after these lectures, based on the patient’s/parents’ needs and with input from the caregiver. Workshops take place with smaller groups and are often run by a two-person team, e.g. an expert and a group leader. These sessions involve doctors (e.g. dermatologists, allergologists, paediatricians), nurses and psychologists.^{2,21} Workshop sessions are usually comprised of patients of a similar age and last around 2 h. The aim of each workshop is to establish an interactive exchange between patient/parents and the caregiver based on a given theme. The educative structure may also involve the use of the internet, as a way of providing patients and parents with information in a format that is accessible, validated and attractive.²² The internet can promote communication and peer-to-peer exchange via social networks and may be useful to help with patient’s or carers’ compliance with educational programmes. It may also promote information exchange through a blog or help eczema centres to propose activities.²

Table 2 Educational resources for learning skills

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

Table 3 Collective sessions

	Lecture	Workshop (groups of 10 participants)
Duration	One or two sessions, 30–90 min	One to three sessions, 30–90 min
Advantages	Capacity to reach a large public	Allows the patients to exchange personal experience (peer-to-peer)
	May lead to individual consultations	Allows the expert to address practical skills (demonstrations) and specific situations (role-playing)
	Mixes all age groups	Allows for the use of interactive tools
Disadvantages	Impersonal information	The need to sort groups according to age
	Acquisition of technical skills is not addressed	
	Impossible to consider individual beliefs and behaviour	

The fourth step concerns the assessment of TPE and is a vital part of the educational process. However, TPE is complex, consisting of different interlinking parts²³ and a large set of criteria is needed to measure TPE efficacy and its assessment should include biomedical outcomes, appropriate psychological scores, QoL scores and medicoeconomic impact (Fig. 3).

Healthcare providers involved in therapeutic patient education programmes in atopic dermatitis

TPE programmes always involve healthcare professionals, although their specific make-up may vary (i.e. nurses, psychologists, doctors, dieticians). Interventions by dermatology nurses

can be helpful.²⁴ Schutellaar et al.^{20,25} explored the level of care provided by nurse practitioners, with respect to improvements in disease severity and QoL measurements, showing that such care was comparable with that provided by a dermatologist. This type of intervention was also cost effective and provided carers with higher levels of satisfaction with regard to the care provided by a nurse practitioner. Nevertheless, educational teams in TPE should be multidisciplinary, be trained in effective TPE and be trained about managing the condition. It is essential that a coherent message is communicated to patients and parents. Thus, whether the educational sessions are being led by a doctor or a nurse, the message must be the same for the different interventions. Although these TPE programmes are designed to be held in a hospital setting, some TPE teams do include private practitioners.¹³ The referral by private practitioners of patients who are in need of support to eczema centres or 'atopic schools' can also highlight the benefits of TPE.

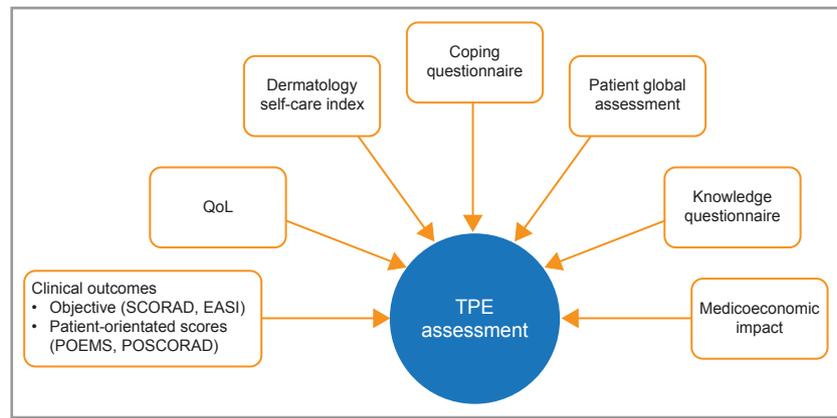
Patient benefit from therapeutic patient education in atopic dermatitis

TPE should not be separated from the therapeutic management of AD.² Thus, effective AD treatment and TPE should be initiated at the same time. TPE should be offered to any patient or carers who have experienced a failure in therapy and to families who feel they lack social support.²⁶ As yet, there have been no studies to establish the time at which TPE should be directed at the child rather than their carers. In practice, TPE programmes tend to be proposed to the parents if a child is below the age of 8 years and to the child themselves if they are between 12 and 18 years.¹³ In any case, an educational programme should always be proposed rather than imposed on a patient, and should be adapted to match each patient's sociocultural background.

Evidence for the benefit of therapeutic patient education in atopic dermatitis

Evaluation of TPE is a complex but essential process. To date, published data have been released by only a few centres. Nevertheless, educational programmes for children with AD and their carers seem to have a positive impact on both disease severity and QoL.^{11,12} Currently, eight randomized, controlled trials have been published that describe TPE programmes for children with AD or their parents.^{19,21,27–32} Out of seven of these trials (QoL was not assessed in one study), TPE appeared to improve QoL in four trials, while disease severity improved in four of the eight trials. However, because the content of the educational programmes used in these studies varies greatly, comparison between these studies is difficult. For example, while the intervention by Staab et al.²¹ entailed 2-h sessions, involving a trained multidisciplinary team, once a week for 6 weeks, the intervention by Shaw et al.³⁰ involved a trained medical student running a single 15-min session. In the three studies that reported no significant effect of TPE on QoL, the duration of the educational intervention was under 30 min. In

Fig 3. Therapeutic patient education (TPE) assessment: examples of outcomes. SCORAD, SCORing of Atopic Dermatitis; EASI, Eczema Area and Severity Index; POEM, Patient-Oriented Eczema Measure; POSCORAD, patient-oriented SCORAD; QoL, quality of life.



the Staab *et al.*²¹ study, 992 children with moderate to severe AD (SCORAD > 20) were randomized. Children between 3 months and 12 years of age were investigated with their parents, while adolescents were treated alone. Statistically more significant improvements were seen in disease severity and QoL over the 12-month period investigated in all three age groups in comparison with controls. Carers of affected children under the age of 7 years reported significantly better improvements in all five QoL subscales compared with the carers of affected children aged between 8 and 12 years, who experienced significantly better improvement in three of the five QoL subscales. Further studies should be conducted in order to compare different educational programmes for their impact on QoL and severity of disease, as well as their effectiveness in terms of durability and cost, their suitability in dermatological practice, and the relevant patient population. As TPE is a complex intervention, tailoring this process to local circumstances may be more effective than generally standardizing it.²³

Funding dermatology therapeutic patient education

The use of TPE in dermatology can be precarious. Most eczema centres have been created without direct financial support, based solely on personal initiatives.¹³ Nevertheless, sources of funding for education programmes do exist: in both France and Germany, health agencies will fund officially recognized education programmes that display regular activity, while in the U.S.A. donations from patients and families provide a source of funding.² In some cases, pharmaceutical companies may provide funding through foundations or donations for the organization of workshops, team training and the development of educative tools. In the U.K. and the U.S.A., large patient associations play a primary role and can be contacted via their websites.

Limits of the therapeutic patient education process

TPE may be refused by patients or their carers, so it is important for caregivers to gauge patient and carer receptiveness to TPE before any programme has begun. There are a number of constraints to TPE, such as availability or schedules, and these should be explained to patients and carers, before making any

decisions. TPE is a time-consuming and costly process, both in private practices and in hospital clinics. Time is required to organize and administer programmes and training for caregivers can be expensive. In certain circumstances, the cost–benefit ratio of initiating a TPE may be unfavourable. Adherence can be hindered by poor literacy, learning or social difficulties, emotional problems, sociocultural backgrounds, limited access to healthcare, treatment costs or psychiatric illness.⁵ Consequently, TPE programmes must be tailored to a patient’s individual educational and cultural background.

Future perspectives

TPE provides an integrated approach to the management of severe AD. It aims to increase a patient’s or carer’s independence, allowing them to adapt their treatment based on the course of their disease and live comfortably with their condition. For the TPE process to be high in quality, it should be focused on the patient’s needs; evidence-based; fully integrated into AD treatment; led by a multiprofessional team with well-defined activities and content; scheduled either within a group or one-to-one sessions; and include an individual assessment to measure the effects of the programme. Future randomized, controlled trials are needed to identify specific modalities that could be more effective than others (e.g. face-to-face nurse-led vs. collective workshops) in improving patients’ and parents’ competence in managing AD. In any instance, TPE may provide the best results if tailored to meet local and cultural patient needs rather than being generically standardized.

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