

Therapeutic Patient Education in Atopic Dermatitis: Worldwide Experiences

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Abstract: Therapeutic patient education (TPE) has proven effective in increasing treatment adherence and improving quality of life (QoL) for patients with numerous chronic diseases, especially atopic dermatitis (AD). This study was undertaken to identify worldwide TPE experiences in AD treatment. Experts from 23 hospitals, located in 11 countries, responded to a questionnaire on 10 major items. Patients in TPE programs were mainly children and adolescents with moderate to severe AD or markedly affected QoL. Individual and collective approaches were used. Depending on the center, the number of sessions varied from one to six (corresponding to 2 to 12 hours of education), and 20 to 200 patients were followed each year. Each center's education team comprised multidisciplinary professionals (e.g., doctors, nurses, psychologists). Evaluations were based on clinical assessment, QoL, a satisfaction index, or some combination of the three. When funding was obtained, it came from regional health authorities (France), insurance companies (Germany), donations (United States), or pharmaceutical firms (Japan, Italy). The role of patient associations was always highlighted, but their involvement in the TPE process varied from one country to another. Despite the nonexhaustive approach, our findings demonstrate the increasing

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interest in TPE for managing individuals with AD. In spite of the cultural and financial differences between countries, there is a consensus among experts to integrate education into the treatment of eczema.

Atopic dermatitis (AD) is a chronic skin condition occurring in children and adults that may affect 5% to 20% of children. Its course is characterized by alternating flares with pruritus and inflammation, on a background of xerosis. AD can be disabling and can markedly affect the quality of life (QoL) of patients and their families.

Topical therapy with creams and ointments is effective, but needs to be adapted daily to the condition of the patient's skin. The success of these treatments depends on the patient's ability to master practical skills—utilizing the right preparation, at the right time, applied to the right place—requiring the active participation of the patient's parents and family members. Failure to treat AD successfully can often be directly linked to poor treatment adherence and even complete cessation of therapy.

Therapeutic patient education (TPE), as defined by the World Health Organization (WHO) (1), is a continuous process of patient-centered medical care. This approach empowers patients to manage their disease by acquiring skills (e.g., self-management, treatment adaptation). Several consensus publications (2,3) have also emphasized the importance of educating patients and their families by combining information dissemination and skill-acquisition techniques (4), which lead directly to better disease management. Finally, patient education has been shown to contribute effectively to preventing complications and improving QoL and treatment adherence for numerous chronic illnesses, such as diabetes, asthma, and cardiovascular disease (5).

Unlike educational programs for other pathologies, TPE is poorly developed in the field of dermatology, although several hospital teams around the world have recently developed educational structures called “eczema centers” or “atopic schools.”

Despite the numerous independent projects that have been developed and reported in Europe (6,7), experience is fragmented and lacks structure. We conducted an international inquiry of experts in this field to compile their experiences and encourage the exchange of skills, tools, and good practices.

MATERIALS AND METHODS

This study was an integral part of the creation of an international network called the Oriented Patient

Education Network in Dermatology (OPENED; <http://www.opened-dermatology.com>), dedicated to TPE in the field of chronic skin diseases.

A questionnaire covering 10 items, which were chosen according to the recommendations of the reference guide published by the French Health Authority (1), was sent to the head of the leading eczema centers (Table 1). The centers included in the survey were selected according to articles published between 2009 and 2010.

RESULTS

All 23 experts, representing 23 hospitals in 11 countries, replied to the questionnaire. The results were presented according to three main headings:

Population: profile, age, symptom severity, number of participants.

Process: type of program, tools used, evaluation of the educative action.

Organization: composition of the education team, involvement of doctors outside the hospital setting, funding, role of patient associations.

Population

The patient profile was characterized by at least one of the three following conditions: moderate to severe AD, significant effect on QoL, and treatment failure. Patients were mainly children or adolescents (20 of 22 centers) except for two centers that held TPE sessions only for adults. Overall, educational programs for adult patients were much less common (7 of 22 hospitals). Patients were stratified by age. The number

TABLE 1. Themes Addressed by the Questionnaire on Therapeutic Education for Atopic Dermatitis

Patient profile: age, symptom severity
Type of educative approach: individual or collective
Program contents and tools used
Number of patients seen per year
Composition of education teams and their training
Mode of evaluating education actions
Relationship with private dermatologists and other health care providers involved with the patient
Center's organization and its funding
General information on education policy in each country
Role of patient associations

of patients participating annually in TPE ranged from 20 to more than 200 per year.

Process

The type of educative approach was categorized as individual or collective (Table 2). Individual sessions were developed in 11 of 23 centers. Most of the time (7 of 10 hospitals), these individual sessions included the participation of two experts: a physician and a nurse. Only in the United Kingdom did a nurse run sessions. The average duration of an individual session was approximately 45 minutes.

Collective sessions (mean duration 2 hours) were organized for groups of approximately 10 patients of similar age in 19 of 23 centers, with the number of sessions varying from one (Belgium) to six (Germany), or as mixed-population meetings of 100 or more patients, often thematic, sometimes monthly (the United States, Brazil, and Denmark). During these workshops, an interactive approach was used in 14 of 23 centers; for the others, the presentation was more academic and informative.

Total TPE duration varied from 1.5 to 12 hours spread out over several weeks (Table 2). Program content was based on theoretical information (e.g., epidemiology, pathogenesis, and disease course) and practical skills information (e.g., application of

treatments, actions to combat itching, prevention of flares). According to the Berlin model (6), the programs developed for collective sessions are structured around several themes: know your illness better (origins, treatments, triggering factors), acquire practical skills (when, where and how to apply treatment), and living with your disease (explaining your disease to others, asking for help during a flare-up). This structured collective approach has been extended to other countries: France, where recommendations were published (8), and Italy, where several atopic schools were created after the first meeting in Milan in 2008 (9).

The tools used in the TPE sessions vary from one center to another. Nonetheless, several hospitals used similar metaphors, such as a burning house for a flare-up (Italy, France, and the United States) or a fireman for corticosteroids (France, Italy, and Belgium). These tools, often created by the TPE teams, include a bus adventure (improving adherence), puppets (identifying symptoms), photo expression (encouraging communication in collective sessions), and songs (remembering processes).

Different tools were used that enabled caregivers to speak about the essential points concerning AD: What are inflammation and skin dryness, and can I recognize them? What are corticosteroids, and when and how should I use them? Although all caregivers

TABLE 2. Types of Education Approaches Used According to Center

Center	Individual approach			Collective approach		
	Yes	Session duration, minutes	Conducted by	Yes	Session duration, minutes	<i>n</i>
Brazil				×	120	3
Canada	×	45	Dermatologist and nurse	×	45	2
Denmark	×	30	Dermatologist and nurse	×	210	2
Germany 1				×	120	6
Germany 2				×	120	6
Germany 3				×	120	6
Italy 1	×		Dermatologist and nurse			
Italy 2	×	45	Dermatologist and pediatrician	×	180	3
Italy 3				×		
United Kingdom 1	×	30	Dermatologist and nurse			
United Kingdom 2				×	90	3
France 1	×	45	Dermatologist and nurse	×	180	3
France 2	×	45	Dermatologist and nurse			
France 3	×	90	Dermatologist and nurse	×	180	3
France 4	×	45	Dermatologist and nurse			
Spain				×		3
Japan 1				×		2
Japan 2				×		8
Belgium 1	×	30	Dermatologist and pediatrician	×	120	1
Belgium 2	×	30–60	Dermatologist and pediatrician	×	90	1
United States 1				×	120	6
United States 2	×		Dermatologist and nurse	×		
Switzerland				×	120	5

used information handouts, and 17 of the centers used interactive education tools, only five centers (Sao Paulo, Brazil; Milan, Italy; Nantes, France; San Diego, CA; and Chicago, IL) offered online support (e.g., videos, podcasts). Official TPE recommendations have been published in Canada, Germany, the United Kingdom, and France.

Patient progress was evaluated mainly according to a clinical score: the Scoring AD (SCORAD) index, Eczema Area and Severity Index (EASI), or Dermatology Life Quality Index. After each workshop, the patient or the parent completed an overall satisfaction evaluation. Economic items were not evaluated in any of the centers.

Organization

The composition of the TPE team was often inter-professional and always interdisciplinary. Physicians (dermatologists, pediatricians, allergists), nurses, psychologists, and dieticians were involved in the educational process. The TPE team received training in 15 of 23 centers. Even though these TPE programs were proposed in hospital settings, private practitioners were involved in some centers (8 of 23).

The relationship with private dermatologists and other health care providers involved with the patient was variable. In theory, each doctor is informed of his or her patient's progress. The private practitioners, who were involved in the hospital team (8 of 23), then used the TPE program in their own practice. Ten of 23 centers mentioned cooperation with other TPE teams (e.g., asthma, allergy).

Funding is an important point in the setting up of eczema centers (Table 3). When funding had been obtained, it was indirect, for example, the nurse's or doctor's salary was paid by the hospital or organization, or direct, meaning it was obtained from insurance companies, charity donations, fundraising, or grants from pharmaceutical companies. Cooperation with patient associations was active in eight of 23 centers (Brazil, Germany, UK, US).

DISCUSSION

In dermatology, AD treatment failure is often linked to poor therapeutic adherence and the fear of using anti-inflammatory agents. These phenomena have led to several new initiatives around the world in the field of AD.

All 23 centers contacted responded to the questionnaire. The TPE offerings of the 23 centers contacted included an individual and a more collective

TABLE 3. *Funding According to Center*

Center	Indirect	Grants	Insurance	Charity	None
Brazil		×		×	
Canada	×				
Denmark	×				
Germany 1			×		
Germany 2			×		
Germany 3			×		
Italy 1					×
Italy 2	×				×
Italy 3					×
United Kingdom 1	×				
United Kingdom 2					×
France 1	×	×			
France 2	×				
France 3	×	×			
France 4	×	×			
Spain	×				
Japan 1		×		×	×
Japan 2					×
Belgium 1		×			
Belgium 2	×	×			
United States 1					×
United States 2	×	×		×	
Switzerland	×				

approach. Individual TPE consists of personal sessions during which the patient's needs and expectations are identified and the practical skills they have to acquire and their learning priorities are established (written action plan). This approach is useful because it enables the doctor to establish the patient's overall profile rapidly so as to customize the TPE program. Another major advantage of individual sessions is that doctors in private practice or nurses in clinics can easily organize them. The limitations of the individual approach reflect the resources needed (time) and the lack of interpatient advice and exchanges.

The survey identified two forms of collective sessions. The first consists of multiannual workshops for more than 100 people. The audience may include parents with children, adult patients, and adolescents. After initially providing general information on AD, less-formal interactive audience participation can occur. These meetings may be monthly (Brazil) or multiannual (Denmark). For patients, these sessions are often the first contact they have with TPE, and the meetings may lead to individual follow-up sessions (Chicago) or structured workshops (Canada and France). This approach is a powerful and efficient way to disseminate information to large numbers of patients. It is also a good way to motivate patients to become involved in a more structured TPE program.

The number of participating patients also varied from one center to another. The difference between the hospitals that integrated education into the normal care process (Germany, France, Belgium, US) and those in which education was based on informative presentations (Japan) may explain this variation.

TPE was mainly evaluated using clinical and QoL scores, but we were unable to collect more precise data (e.g., patient skills, treatment adherence). Evaluation of TPE is an important step, albeit a difficult one, and only a few centers have been able to publish their data (9–11). The German Atopic Dermatitis Intervention Study (GADIS) was the first to demonstrate TPE efficacy using evidence-based criteria by determining the effects of age-related, structured TPE on the management of moderate to severe AD in children and adolescents in a multicenter, randomized controlled trial (11). The GADIS results showed that, compared with standard care, six group sessions of 2 hours per week resulted in sustained attenuation of AD severity, as assessed with the SCORAD index, and better QoL (12).

Most of the eczema centers were created on the basis of personal initiatives without any direct financial aid. Setting up a TPE program depends mostly on the power of individual leaders or “experts,” who in turn enable motivated team members to be involved in AD education. The funds available to provide TPE in the institutions are almost nonexistent and are usually linked to grants from pharmaceutical companies or patient associations or their fundraising, although, in accordance with selective criteria, the Federal Ministry of Health in Germany and the regional health agencies in France officially recognize eczema centers and atopic schools.

This inquiry had some limitations. The centers included in the survey were selected according to articles published between 2009 and 2010. Considering the recent rapid development of TPE around the world, the centers included in the study do not represent a complete overview of the educative approaches in TPE for AD.

Compared with diabetes or cardiovascular TPE programs, the lack of official recommendations in AD programs is significant. Without validated recommendations, most hospitals are not in a position to offer a formal and recognized program for their team such as the asthma or diabetes centers offer. Only Germany and France had official training programs for the TPE team members. International consensus recommendations for TPE for AD patients are being prepared.

Patient associations are also often powerful lobbies and have fundraising possibilities. In the United Kingdom and the United States, large patient associations play a primary role and can be contacted through their Web sites.

Finally, the evaluation of TPE is an important point before obtaining formal recognition of the educational process from the relevant health authorities (13). Medico-economic evaluation in AD is more difficult to accomplish than with severe asthma or diabetes. The integration of the new self-assessment scores such as patient-oriented SCORAD (14) or Self-Administered EASI (15) could provide more regular follow-up of the patient’s eczema course between evaluations. In the future, these tools may be an important aspect of assessing TPE as they can provide investigators with access to continuous self-assessments of the effect of TPE on the patient’s AD management (16). Moreover, the medico-economic approach to TPE must be explored in light of the high financial costs of severe AD.

Despite the cultural differences between countries, the OPENED experts’ consensus that TPE must be integrated into AD patient-centered medical care has led them to prepare recommendations to facilitate the performance of future multicenter studies and better evaluate the real effect of TPE on the management of individuals with AD. Furthermore, comparative studies could help identify specific modalities that would be more effective than others in achieving the aim of improving patients’ and parents’ confidence and competence in managing chronic AD.

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REFERENCES

1. Therapeutic patient education: definition, goal and organisation; Haute Autorité de Santé (HAS)[on-line]. http://www.has-sante.fr/portail/upload/docs/application/pdf/2008-12/therapeutic_patient_education_tpe_-_developing_a_tpe_programme_-_quick_reference_guide.pdf
2. Proceedings of the consensus conference on the management of atopic dermatitis in children. *Ann Dermatol Venereol* 2005;132:1S5-1S290
3. Akdis CA, Akdis M, Bieber T et al. Diagnosis and treatment of atopic dermatitis in children and adults: European Academy of Allergy and Clinical Immunology/American Academy of Allergy, Asthma and Immunology. *J Allergy Clin Immunol* 2006;11:152-169.
4. Wenninger K, Kehrt R, von Räden U et al. Structured parent education in the management of childhood atopic dermatitis: the Berlin model. *Patient Educ Couns* 2000;40:253-261.
5. Guevara JP, Wolf FM, Grum CM et al. Effects of educational interventions for self-management of asthma in children and adolescents: systematic review and meta-analysis. *BMJ* 2003;326:1308-1309.
6. Broberg A, Kalimo K, Lindblad B et al. Parental education in the treatment of childhood atopic eczema. *Acta Derm Venereol (Stockh)* 1990;70:495-499.
7. Gieler U, Koehnlein B, Schauer U et al. Elternberatung bei Kindern mit atopischer dermatitis (counselling of parents with children with atopic dermatitis). *Hautarzt* 1992;43:37-42.
8. Barbarot S, Gagnayre R, Bernier C et al. Groupe education thérapeutique de la société française de dermatologie a guide for education programs in atopic dermatitis. *Ann Dermatol Venereol* 2007;134:121-127.
9. Ricci G, Bendandi B, Alazzi R et al. Three years of Italian experience of an educational program for parents of young children affected by atopic dermatitis: improving knowledge produces lower anxiety levels in parents of children with atopic dermatitis. *Pediatr Dermatol* 2009;26:1-5.
10. Chavigny JM, Adiceom F, Bernier C et al. Assessment of an educational program in an "atopic school": pilot study in 40 patients. *Ann Dermatol Venereol* 2002;129:1003-1007.
11. Williams HC. Educational programmes for young people with eczema. *BMJ* 2006;332:923-924.
12. Staab D, Diepgen T, Fartasch M et al. Age-related, structured educational programmes for the management of atopic dermatitis in children and adolescents: multicentred, randomised controlled trial. *BMJ* 2006;332:933-938.
13. Ersser SJ, Latter S, Sibley A et al. Psychological and educational interventions for atopic eczema in children [review]. *Cochrane Database Syst Rev* 2009 [online]. <http://www2.cochrane.org/reviews/en/ab004054.html>
14. Vourc'h-Jourdain M, Barbarot S, Taieb A et al. Patient-oriented SCORAD: a self-assessment score in atopic dermatitis. A preliminary feasibility study. *Dermatology* 2009;218:246-251.
15. Van Velsen SG, Knol MJ, Haecck IM et al. The self-administered eczema area and severity index in children with moderate to severe atopic dermatitis: better estimation of AD body surface area than severity. *Pediatr Dermatol* 2010;27:470-475.
16. Stalder J-F, Barbarot S, Wollenberg A et al. Patient-oriented SCORAD (PO-SCORAD): a new self-assessment scale in atopic dermatitis validated in Europe. *Allergy* 2011;66:1114-1121.