Therapeutic education in atopic dermatitis: A position paper from the International Eczema Council

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TPE-IEC position paper

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Abbreviations used: AD (atopic dermatitis), TPE (therapeutic patient education), QOL (quality of life), EAP (eczema action plan), EASI (Eczema Area and Severity Index), SCORAD (scoring atopic dermatitis), PO-SCORAD (patient-oriented SCORAD)

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Abstract

Background: Atopic dermatitis (AD) is a chronic, inflammatory skin disease that affects as many as 12.5% of children aged 0-17 and 3% of the adult population. In the United States, 31.6 million children and adults are estimated to be living with AD.

Objective: Therapeutic patient education (TPE) has proven its value in the management of chronic diseases for which adherance to therapy is suboptimal. This article explores experts' opinions and treatment practices to determine if TPE is a recommended and effective method for treating AD.

Methods: An electronic survey on TPE and AD was sent to 42 Councilors and Associates of the International Eczema Council (IEC), an international group with expertise in AD. The response rate was 100%.

Results: Most respondents (97.5%) agreed that TPE should play an important role in the management of AD. Many respondents (82.9%) believed that all patients with AD, regardless of disease severity, could benefit from TPE.

Limitations: The IEC survey lacks specific information on AD severity.

Conclusions: Publications have shown the positive effect of TPE on the course of the disease, the prevention of complication, and the autonomy and quality of patient life. Survey respondents agreed that TPE can improve quality of patient care and patient satisfaction with care.

Capsule Summary

- Studies have examined the effectiveness of Therapeutic Patient Education with evidence suggesting a positive impact on patient outcomes. Its effect on Atopic dermatitis was explored via survey of experts.
- Summary review of Therapeutic Patient Education and experts' opinions illustrates how Therapeutic Patient Education can improve quality of care and patient satisfaction in clinical practice.

Introduction

Atopic dermatitis (AD) is a chronic, inflammatory skin disease that is estimated to affect 12.5% of children aged 0-17 and 3% of the adult population[1].

For atopic dermatitis, topical therapies remain the mainstay for most patients, but patient adherence to topical therapies is dishearteningly low[2].

As many recommendations point out, therapeutic patient education (TPE) is now part of the management of AD.[2]

The International Eczema Council (IEC) brings together scientists and physicians dedicated to research, education, and the optimal management of AD for patients and families. To assess the role of TPE in the management of the disease, the IEC conducted a survey of its members.

This article reports on the role of TPE in chronic diseases in general and the peculiarities of TPE in AD. The types of TPE delivery and their advantages and disadvantages are discussed, and the results of the survey are presented in a final chapter.

Therapeutic patient education (TPE) in chronic diseases

Over the past several decades in North America and Europe, the role of physicians has shifted from experts "who decide what was right for any patient without consulting the patient's wishes or preferences" to equal partners who are expected to play an active role in educating patients about their disease.[3,4] Patients, once expected to be unquestioning and passive, now weigh treatment options and participate in shared decision making with their healthcare providers. Patient education rose to prominence in the 1970s in parallel with the establishment of patient advocacy groups and was applied to topics as disparate as hygiene, dental health, healthy diet, and exercise.[4] The terms "patient education" and 'therapeutic patient education" are sometimes used interchangeably, but generally, the prefix "therapeutic" indicates guidance directed at management of a disease[5].

TPE has proven its value in the management of numerous chronic diseases for which adherance to therapy is suboptimal, such as congestive heart failure[6], diabetes mellitus[7], asthma[8], and rheumatoid arthritis[9].

In all chronic diseases, adherance to treatment ranges from 30% to 40% due mainly to a lack of TPE.[10]

In chronic and life-altering diseases other than AD, thoughtfully designed TPE interventions have demonstrated not only the power to increase knowledge of the disease but also to improve quality of life (QOL), strengthen alignment of patient and provider goals, and even promote trust and self-expression.

A recent critical analysis of 35 meta-analyses between 1999 and 2009 concluded that 64% of studies across all diseases found improvement of patient outcomes with TPE.[11]

The difficulties of living with AD

The visible and chronic nature of AD can lead to feelings of helplessness, frustration, self-consciousness about appearance, avoidance of activities, and a negative impact on social relationships. Children with AD often have poor/interrupted sleep, restricted diet, behavior and discipline problems, hyperactivity, irritability, restlessness, restricted outdoor play, and restricted clothing and are often avoided by other children and adults[12].

Parents and caregivers also experience significant stress, often citing their helplessness to stop their children from scratching and their inability to reduce their children's suffering. Parents

of children with AD are more likely to suffer anxiety and depression, which may be related to perception of their children as vulnerable.[13]

Just as scratching and pruritus reinforce each other in AD, psychosocial stress factors are also involved in the itch-scratch cycle. A stressful event can induce a perception of itch and increased restlessness, both of which ultimately promote scratching. Interrupting this vicious circle with effective and correctly applied treatments is the goal of therapy for AD patients.[14]

Treatment challenges leading to poor adherence

Poor adherence to therapy has many causes, and one particularly prominent cause is fear of topical corticosteroids (dubbed "corticophobia") and other therapies due to Internet-disseminated misinformation and selective reporting of highly unusual cases. Standard cautionary labelling of topical steroids also contributes to patients' reluctance to adequately apply topical therapies.[4]

All patients with AD potentially benefit from improved basic skincare, including regular use of emollients, emollient application after bathing, and avoidance of irritating fabrics; patients with more severe disease may see improvement from bleach baths and/or wet wraps, as well. These lifestyle changes and procedural interventions require teaching. Ensuring that patients receive adequate therapy outside the clinical setting requires the effective exchange of skills and knowledge between patients and healthcare providers. TPE can provide that exchange.

Frameworks for TPE in AD

Emanuel and Emanuel described four models by which physicians can interact with patients: paternalist, informative, interpretative, and the deliberative. The first three models are physician-centered, butthe deliberative model, in which physicians and patients share decision making, is patient-centered.[15] As with other TPE interventions, TPE for AD should be patient-centered. TPE should not be forced upon patients.

The first step of any therapeutic intervention is assessment of patients' beliefs, fears, hopes, and interest in learning more about their disease. Gagnayre calls this the "educational diagnosis,"[16] to be followed by determination of the age-appropriate skills and knowledge needed by the patient/family, which he terms "educational objectives." Skills are then acquired at individual sessions, at collective workshops, at demonstrations, or through a personalized action plan. Finally, assessment is required to determine the success or failure of the therapeutic intervention and to fine-tune the intervention for future patients. Gagnayre's framework has been applied to AD patients.[16]

A critical first step in TPE for AD is assessment of patient (and parental in the case of pediatric patients) concerns, priorities, understanding of disease, and willingness to participate. In pediatric dermatology, cost and safety of prescribed medications are a common source of parental concern.[13] Misunderstanding of the natural course of AD by patients/parents also may be a barrier to care, because unrealistic expectations may lead to undue frustration with relapses of disease. Other barriers to care, including forgetfulness and complexity of treatment, also should be carefully identified and discussed with patients and family members at this first stage. Barbarot et al. developed a detailed guide to organizing this initial session with specific questions designed to elicit concerns and priorities from patients and parents.[17]

Once objectives have been established, an eczema action plan (EAP) should be created, agreed upon, and signed by all parties. Randomized-controlled trials have shown that EAPs can improve patient understanding of the daily treatment plan, application location and duration, exacerbating factors, and the need to adjust treatment to severity, according to the treatment

plan.[18] The majority of patients find EAPs useful.[18] For greatest success, EAPs should enumerate stepwise treatment and include visual diagrams and daily reminders.[18]

There is no single "right way" to provide TPE, given that improvement in outcomes has been seen with multiple modes of education. Individual appointments with trained nurses have been shown to be effective in improving outcomes in AD,[19] as have structured lecture and small group sessions stratified by age[20], and online videos.[21] These delivery methods also have been effective in other diseases for which TPE has been successful.

Evidence for the benefit of TPE in AD

Numerous studies have examined the effectiveness of TPE for AD in randomized clinical trials,[18] with evidence overall suggesting a positive impact of TPE on outcomes such as disease severity, treatment adherence, QOL, and coping with itch.[17] Studies vary in terms of interventions studied, including multisession group workshops facilitated by multidisciplinary teams (e.g., dermatologists, nurses, psychologists, dietitians), as well as nurse-led educational sessions. In several studies that did not find a significant effect of TPE on QOL, the educational component was less than 30 minutes, highlighting the importance of comprehensive TPE. Recently, a prospective, randomized-controlled multicenter study in Germany investigated the effect of a comprehensive 12-hour training manual for adult patients. This educational program showed significant beneficial effects on a variety of psychosocial parameters in addition to AD severity.[22]

There is some evidence for the cost-effectiveness of TPE. However, more trials are needed to compare different program methods to standard treatment using outcomes such as treatment and prescription costs, number of hospital days, and indirect costs such as missed school or lost wages.[23]

Methods

A 28-question electronic questionnaire (TAB I) was developed by the IEC's TPE task force and sent to all 82 IEC Councilors and Associates. Responses were discussed in February 2018 at a Councilor and Associate session in San Diego, California.

Results

Forty-two (51%) Councilors and Associates responded to the survey, representing many countries and regions: Asia, Australia, Canada, Europe, India, South America, the Middle East, the United Kingdom, and the United States.

Nearly one-third of respondents see more than 100 patients with AD per month. Subjects discussed were the following:

- *Patient profile:* On average, 20% of these providers' patients had mild AD, 45% had moderate AD, and 35% had severe AD.
- *TPE and AD management:* Nearly all respondents (97.5%) agreed that TPE should play an important role in the management of persistent, treatment-refractory AD. Most respondents (82.9%) also believed that all patients with AD, regardless of severity, could benefit from TPE.
- *Circumstances in which TPE is appropriate:* TPE was appropriate, respondents said, in cases of treatment failure (92.1%), corticosteroid phobia (87.8%), high financial or psychosocial burden of disease (85.4%), lack of patient motivation (80.5%), and disease severity that warrants systemic therapy (82.9%).
- *Practical organization and setting:* 51% of respondents do not use an atopy school. The

most common reported setting for TPE is an in-office visit. It is likely that in-office TPE is not delivered through a formalized team-based program.

- *Contrasting experiences:* There are clear differences between the formal German program of atopy school which demonstrated efficacy according to evidence-based criteria[29] and the Brazilian experience in which 75% of patients indicated AD improvement after having attended an informal support group.
- *Tools:* Most of the respondents (80.0%) reported providing TPE tools, including handouts, videos, photos and order sets, to patients and their caregivers. Many also reported providing materials to other physicians, residents, nurses, pharmacists, etc. Thissuggests that TPE tools can have the added benefit of educating allied healthcare professionals.
- *Propositions:*
  - Specialist dermatological nurses providing a formal model of TPE could offer an efficient alternative to current TPE delivery methods.
  - Specialists are developing online forums, and web-based programs for the delivery of TPE.
  - A promising recent development was the educational training of other healthcare providers during training sessions (TPE Day) in France, Canada, and the USA.
- *Outcome assessment:*
  - Most providers (80.0%) reported relying on patients' informal assessment of whether their AD is better or worse.
  - Many respondents (70.0%) regularly use formal physician assessments of disease severity (e.g., EASI, SCORAD).
  - Patient-reported outcomes are useful tools to motivate and help patients manage their disease over long periods; PO-SCORAD is effective and fast in measuring eczema lesions, itch, and sleeplessness.[24,25]
  - All survey respondents agreed that TPE can improve quality of patient care and patient satisfaction with care.
- *Obstacles:*
  - TPE is more complex than just giving patients handouts or showing instructional videos.
  - TPE providers need training.
  - TPE is a time-consuming process, and the lack of funding and excessive bureaucracy limit its practical implementation.

Survey comments from respondents

All experts who responded to the survey have extensive experience in the treatment of AD and agreed that TPE is an appropriate response to therapeutic failure, regardless of its cause. But the debate was colored by how the word "education" is perceived. The informative approach (directing patients to web sites and giving them brochures) is widely accepted and applied with only a few experts using the deliberative (patient-centered) approach seen in the atopic school.

These two complementary approaches (informative and deliberative) led to the following comments from respondents regarding TPE:

- Multiple messages communicated by multiple healthcare providers (including pharmacists) can create confusion among patients and lead to corticophobia.
- General information given to patients is often counterproductive. Patients need

information about their specific problems, and it is imperative to begin the educative process this way.

- The patient-centered approach used in atopic schools (German model) [20,22] is not easily exportable to different cultural and economic contexts.
- Nurses play an essential role in encouraging communication with patients. Experts highlighted the positive role of specialist nurses to explain hygiene in cases of mild disease. Their integration into the medical teams is recommended.
- The idea of developing high quality e-learning tools using artificial intelligence is an interesting suggestion.
- E-learning tools should be adapted for use by specific healthcare providers (e.g., pharmacists, nurses).
- To improve the evidence-based quality of TPE, there is a need to develop patient-reported outcome tools capable of assessing acquired skills.

Conclusion

TPE has become indispensable for managing chronic diseases. Multiple publications have shown the positive effect of TPE on the course of the disease, the prevention of complications, and the autonomy and quality of patient life.

In AD, TPE is increasingly proposed as a means to increase treatment adherence, to avoid treatment failure, and to improve the patient QOL. IEC expert clinicians, most of whom are hospital-based, responded to and discussed a 28-question survey. Their responses heighten physician awareness of the crucial role of TPE. They concluded that TPE can improve quality of patient care and patient satisfaction with care and that there is much to be done in this area compared to the advances in TPE for other chronic conditions.

TPE approaches depend on considerations that include the clinical setting, country and its organization of health services, and socioeconomic and cultural factors.
In the future, digital tools could create new opportunties for research by assisting in the rescruitment of patients, calculation of cost-benefit ratio assessment, and other study-related work.

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Table and Figure

TABLE 1 - Collective sessions PROS and CONS

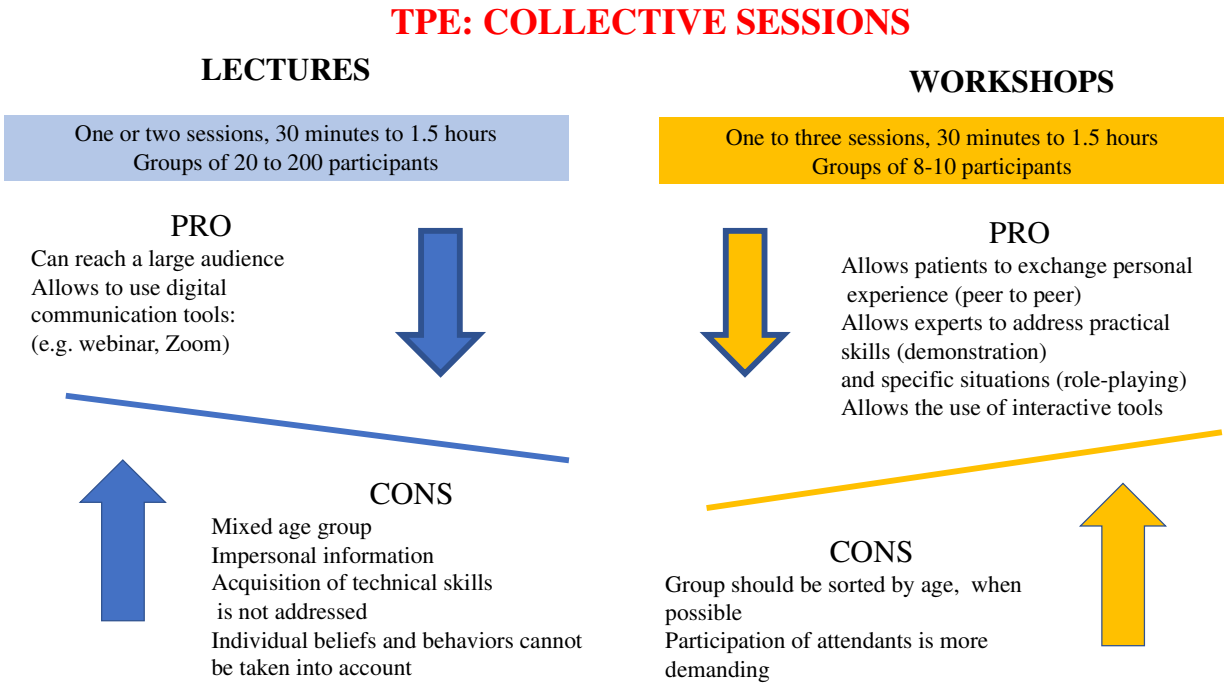

Figure Legend:

Collective sessions for TPE in AD

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405 In this table we can see and compare the advantages and disadvantages that result from the

406 implementation of TPE in AD through lectures and workshops.