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

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TPE-IEC position paper

1 **Therapeutic Education in Atopic Dermatitis:** 2 **A position paper from the International Eczema Council**

3
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5
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36 of life), EAP (eczema action plan), EASI (Eczema Area and Severity Index), SCORAD (scoring
37 atopic dermatitis), PO-SCORAD (patient-oriented SCORAD)

38
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40 corticosteroids, therapeutic education, eczema action plan, e-learning, pruritus.

41
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78 conflicts of interest to declare.

81 **Abstract**

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

85
86 **Objective:** Therapeutic patient education (TPE) has proven its value in the management of
87 chronic diseases for which adherence to therapy is suboptimal. This article explores experts'
88 opinions and treatment practices to determine if TPE is a recommended and effective method for
89 treating AD.

90

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

94
95 **Results:** Most respondents (97.5%) agreed that TPE should play an important role in the
96 management of AD. Many respondents (82.9%) believed that all patients with AD, regardless of
97 disease severity, could benefit from TPE.

98
99 **Limitations:** The IEC survey lacks specific information on AD severity.

100
101 **Conclusions:** Publications have shown the positive effect of TPE on the course of the disease,
102 the prevention of complication, and the autonomy and quality of patient life. Survey respondents
103 agreed that TPE can improve quality of patient care and patient satisfaction with care.

104

105 **Capsule Summary**

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

112

113

114 **Introduction**

115 Atopic dermatitis (AD) is a chronic, inflammatory skin disease that is estimated to affect
116 12.5% of children aged 0-17 and 3% of the adult population¹.

117 For atopic dermatitis, topical therapies remain the mainstay for most patients, but patient
118 adherence to topical therapies is dishearteningly low².

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

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

125 This article reports on the role of TPE in chronic diseases in general and the peculiarities
126 of TPE in AD. The types of TPE delivery and their advantages and disadvantages are discussed,
127 and the results of the survey are presented in a final chapter.
128

129 **Therapeutic patient education (TPE) in chronic diseases**

130 Over the past several decades in North America and Europe, the role of physicians has
131 shifted from experts “who decide what was right for any patient without consulting the patient’s
132 wishes or preferences” to equal partners who are expected to play an active role in educating
133 patients about their disease.^{3,4} Patients, once expected to be unquestioning and passive, now
134 weigh treatment options and participate in shared decision making with their healthcare providers.
135 Patient education rose to prominence in the 1970s in parallel with the establishment of patient
136 advocacy groups and was applied to topics as disparate as hygiene, dental health, healthy diet,
137 and exercise.⁴ The terms “patient education” and “therapeutic patient education” are sometimes
138 used interchangeably, but generally, the prefix “therapeutic” indicates guidance directed at
139 management of a disease⁵.

140 TPE has proven its value in the management of numerous chronic diseases for which
141 adherence to therapy is suboptimal, such as congestive heart failure⁶, diabetes mellitus⁷, asthma⁸,
142 and rheumatoid arthritis⁹.

143 In all chronic diseases, adherence to treatment ranges from 30% to 40% due mainly to a
144 lack of TPE.¹⁰

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

149 A recent critical analysis of 35 meta-analyses between 1999 and 2009 concluded that 64%
150 of studies across all diseases found improvement of patient outcomes with TPE.¹¹
151

152 **The difficulties of living with AD**

153 The visible and chronic nature of AD can lead to feelings of helplessness, frustration, self-
154 consciousness about appearance, avoidance of activities, and a negative impact on social
155 relationships. Children with AD often have poor/interrupted sleep, restricted diet, behavior and
156 discipline problems, hyperactivity, irritability, restlessness, restricted outdoor play, and restricted
157 clothing and are often avoided by other children and adults¹².

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

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

162 Just as scratching and pruritus reinforce each other in AD, psychosocial stress factors are
163 also involved in the itch-scratch cycle. A stressful event can induce a perception of itch and
164 increased restlessness, both of which ultimately promote scratching. Interrupting this vicious
165 circle with effective and correctly applied treatments is the goal of therapy for AD patients.¹⁴
166

167 **Treatment challenges leading to poor adherence**

168 Poor adherence to therapy has many causes, and one particularly prominent cause is fear
169 of topical corticosteroids (dubbed “corticophobia”) and other therapies due to Internet-
170 disseminated misinformation and selective reporting of highly unusual cases. Standard cautionary
171 labelling of topical steroids also contributes to patients’ reluctance to adequately apply topical
172 therapies.⁴

173 All patients with AD potentially benefit from improved basic skincare, including regular
174 use of emollients, emollient application after bathing, and avoidance of irritating fabrics; patients
175 with more severe disease may see improvement from bleach baths and/or wet wraps, as well.
176 These lifestyle changes and procedural interventions require teaching. Ensuring that patients
177 receive adequate therapy outside the clinical setting requires the effective exchange of skills and
178 knowledge between patients and healthcare providers. TPE can provide that exchange.
179

180 **Frameworks for TPE in AD**

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

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

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

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

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

209 There is no single “right way” to provide TPE, given that improvement in outcomes has
210 been seen with multiple modes of education. Individual appointments with trained nurses have
211 been shown to be effective in improving outcomes in AD,¹⁹ as have structured lecture and small
212 group sessions stratified by age²⁰, and online videos.²¹ These delivery methods also have been
213 effective in other diseases for which TPE has been successful.

214 215 **Evidence for the benefit of TPE in AD**

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

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

230 231 **Methods**

232 A 28-question electronic questionnaire (TAB I) was developed by the IEC’s TPE task
233 force and sent to all 82 IEC Councilors and Associates. Responses were discussed in February
234 2018 at a Councilor and Associate session in San Diego, California.

235 236 **Results**

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

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

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

- 253 most common reported setting for TPE is an in-office visit. It is likely that in-office TPE
254 is not delivered through a formalized team-based program.
- 255 • *Contrasting experiences:* There are clear differences between the formal German program
256 of atopy school which demonstrated efficacy according to evidence-based criteria²⁹ and
257 the Brazilian experience in which 75% of patients indicated AD improvement after
258 having attended an informal support group.
 - 259 • *Tools:* Most of the respondents (80.0%) reported providing TPE tools, including handouts,
260 videos, photos and order sets, to patients and their caregivers. Many also reported
261 providing materials to other physicians, residents, nurses, pharmacists, etc. This suggests
262 that TPE tools can have the added benefit of educating allied healthcare professionals.
 - 263 • *Propositions:*
 - 264 ○ Specialist dermatological nurses providing a formal model of TPE could offer an
265 efficient alternative to current TPE delivery methods.
 - 266 ○ Specialists are developing online forums, and web-based programs for the delivery
267 of TPE.
 - 268 ○ A promising recent development was the educational training of other healthcare
269 providers during training sessions (TPE Day) in France, Canada, and the USA.
 - 270 • *Outcome assessment:*
 - 271 ○ Most providers (80.0%) reported relying on patients' informal assessment of
272 whether their AD is better or worse.
 - 273 ○ Many respondents (70.0%) regularly use formal physician assessments of disease
274 severity (e.g., EASI, SCORAD).
 - 275 ○ Patient-reported outcomes are useful tools to motivate and help patients manage
276 their disease over long periods; PO-SCORAD is effective and fast in measuring
277 eczema lesions, itch, and sleeplessness.^{24,25}
 - 278 ○ All survey respondents agreed that TPE can improve quality of patient care and
279 patient satisfaction with care.
 - 280 • *Obstacles:*
 - 281 ○ TPE is more complex than just giving patients handouts or showing instructional
282 videos.
 - 283 ○ TPE providers need training.
 - 284 ○ TPE is a time-consuming process, and the lack of funding and excessive
285 bureaucracy limit its practical implementation.

287 **Survey comments from respondents**

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

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

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

- 298 information about their specific problems, and it is imperative to begin the educative
299 process this way.
- 300 • The patient-centered approach used in atopic schools (German model)^{20,22} is not
301 easily exportable to different cultural and economic contexts.
 - 302 • Nurses play an essential role in encouraging communication with patients. Experts
303 highlighted the positive role of specialist nurses to explain hygiene in cases of mild
304 disease. Their integration into the medical teams is recommended.
 - 305 • The idea of developing high quality e-learning tools using artificial intelligence is an
306 interesting suggestion.
 - 307 • E-learning tools should be adapted for use by specific healthcare providers (e.g.,
308 pharmacists, nurses).
 - 309 • To improve the evidence-based quality of TPE, there is a need to develop patient-
310 reported outcome tools capable of assessing acquired skills.
- 311

312 Conclusion

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

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

322 TPE approaches depend on considerations that include the clinical setting, country
323 and its organization of health services, and socioeconomic and cultural factors.

324 In the future, digital tools could create new opportunities for research by assisting in the
325 recruitment of patients, calculation of cost-benefit ratio assessment, and other study-
326 related work.

327

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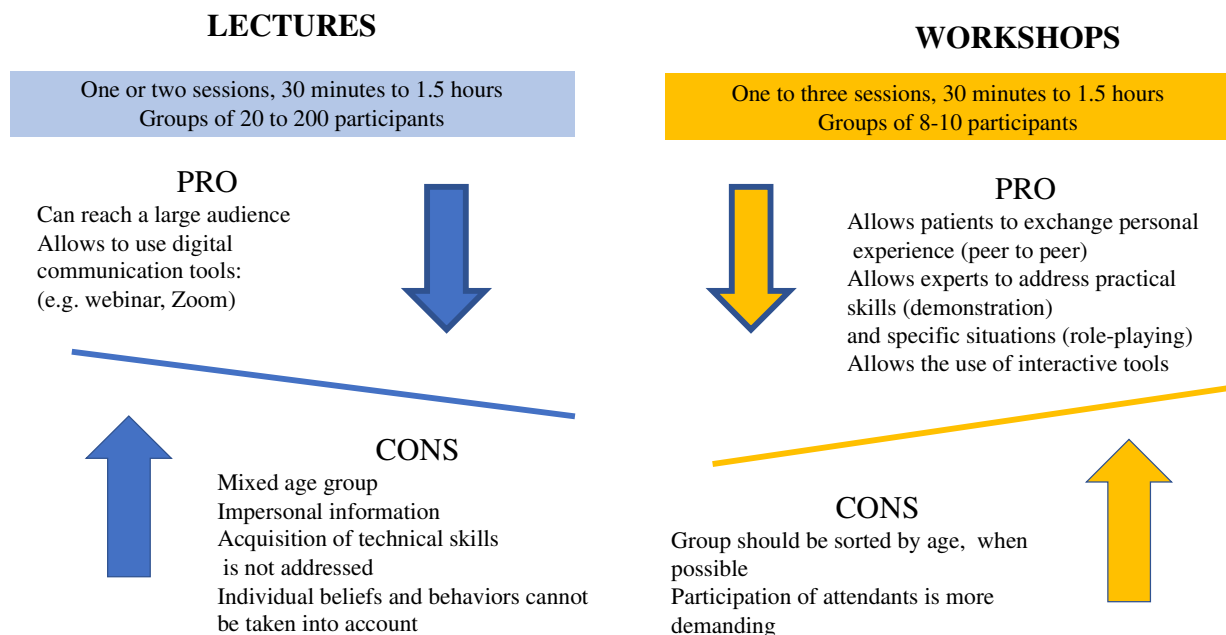
390 **Table and Figure**

391

392

393 **TABLE 1** - Collective sessions PROS and CONS

TPE: COLLECTIVE SESSIONS



394

395

396

397

398

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400

401 **Figure Legend:**

402

403 **Collective sessions for TPE in AD**

TPE-IEC position paper

404

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.