

Atopic dermatitis: therapeutic care delivery: therapeutic education, shared decision-making, and access to care

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■ Abstract

Atopic dermatitis (AD) is a chronic skin condition affecting children and adults, with a significant negative impact on patient and caregiver quality of life (QOL). Although effective treatments for AD are available, outcomes are often limited by poor adherence to treatment plans. Effective patient and caregiver education about the disease and its management is a necessary and important component of AD care. Therapeutic patient education (TPE) is a patient-centered process that aims to transfer information and skills necessary to manage and cope with a disease from health care professionals to patients and caregivers. Shared decision making between the health care provider and the patient/caregiver is an integral component of the TPE process and recognizes the importance of both the medical provider's clinical expertise, as well as the patient/caregiver's preferences and experiences regarding their own medical condition and its treatment. TPE programs for patients with AD and their caregivers are typically provided by multidisciplinary teams and utilize a number of different methods and tools to facilitate the transfer of knowledge and skills through both individual care and group-based educational sessions. TPE has been demonstrated to improve outcomes such as AD disease severity, treatment adherence, QOL, and coping with itch. It is important to consider strategies to reduce barriers to cost-effective accessible AD education and treatment.

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Atopic dermatitis (AD) is the most prevalent skin disorder among the pediatric population, estimated to affect 10% to 20% of children and 1% to 3% of adults.^{1,2} The disease has a significant impact on quality of life (QOL). Patients suffer intense, frequent pruritus and sleep is significantly disrupted in over 60% of patients and caregivers.^{3,4} The visible and chronic nature of the disease can lead to feelings of helplessness, frustration, self-consciousness about appearance, avoidance of activities, and a negative impact on social relationships.⁵ There is an increased risk of mental health conditions such as attention-deficit hyperactivity disorder (ADHD), depression, and anxiety among pediatric and adult patients with AD.^{6,7} Financial burden associated with AD is significant and includes both direct costs such as physician visits, prescriptions, and over-the-counter costs, as well as indirect costs such as absenteeism from work and reduced productivity.⁸

Although effective treatments for AD are available, they must be used regularly and accurately over an extended period of time.⁹⁻¹¹ Patient nonadherence to outpatient management plans may lead to therapeutic failure or ultimately to hospitalizations, which have recently been estimated to cost over \$125 million per year in the United States.^{12,13} Many factors limit adherence to AD management plans. Skincare routines are often time intensive and complex.¹⁴ A common complaint among AD patients is that the time allocated in a typical visit to a physician does not allow for true understanding of the answers to all of their questions.¹⁵ Dermatology treatments and medications are often presented within brief consults, with little time for truly comprehending and digesting important information. There are many new medications for the treatment of AD, which only adds to the

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TABLE 1 Interview guide for assessing patient experiences and preferences regarding atopic dermatitis management

What factors worsen or improve your disease?
What things does your disease make it harder to do?
What's the aspect of your disease that bothers you the most?
What's the cause of your disease, in your opinion?
How is the treatment going? Describe in detail what you do.
What concerns do you have about your treatment?
What gets in the way of treatment?

Adapted from Barbarot S, Bernier C, Deleuran M, et al. Therapeutic patient education in children with atopic dermatitis: position paper on objectives and recommendations. *Pediatr Dermatol*. 2013;30(2):199-206.²⁴

patient confusion regarding topical and systemic use.¹⁶ This uncertainty can affect patient compliance, increase disease relapse, and magnify potential medication side effects. Patients may have fears about side effects of treatment, such as concerns about skin thinning, medication passing through the skin to the blood stream, negative impact on growth and development with topical steroid use, as well as concerns about black-box warnings for topical calcineurin inhibitors.^{17,18} Lack of understanding of drug potencies and the chronicity of the disease may also impact adherence to topical medications.¹⁸ Some patients report burning or stinging with baths or topical medications/moisturizers, or issues with acceptability of treatments (eg, “messy,” “sticky,” or uncomfortable emollients or wraps), which commonly affect child cooperation with skincare.¹⁸⁻²⁰

Effective patient and caregiver education about the disease and its management is a necessary and important component of AD care. Therapeutic patient education (TPE) and shared decision-making are promising approaches for facilitating improved therapeutic adherence, health outcomes, and QOL for patients with AD and their families.

Patient-centered care: underlying principles of therapeutic patient education and shared decision-making

Therapeutic patient education is defined by the World Health Organization as an approach to help patients with chronic illness to acquire or maintain the skills necessary to manage their life and illness in the best way possible. This involves a transfer of information and skills to manage and cope with the disease from the provider to the patient and/or caregiver in order to support patient autonomy.²¹ TPE is already in use in the treatment of many chronic diseases and represents a particularly relevant approach in the case of AD, as patients and their families are directly responsible for assessing the condition of the skin on a daily basis and adapting local treatment accordingly.²²⁻²⁴

TPE is a patient-centered process. The patient's experiences and preferences are integrated into the care process, through

shared decision-making with the medical provider in the development of the treatment plan.^{21,24} Shared decision-making recognizes the importance of the medical provider's clinical expertise as well as the patient/caregiver's expertise regarding their own illness. Dermatologic disease are particularly good fits for shared decision-making as disease severity is defined in part by patient experience of symptoms and impact on QOL.²⁵ Treatment decisions thus take into account patient and caregiver values, goals, preferences, and circumstances, which in the case of AD, may include factors such as risks/side effects, convenience of treatment, product acceptability, mode of administration, onset and overall efficacy, and treatment cost.²⁵ Shared decision-making is a “deliberative model” of the physician-patient relationship, which involves engaging patients/caregivers in collaborative, evaluative discussions of health issues and related values, as opposed to more paternalistic models (“physician knows best”) or informative models (physician provides all options and patient decides).²⁶

Components of the TPE process

Consensus recommendations developed by an international group of multi-specialty health care providers outline a 4-step process for transferring knowledge and skills (self-management, treatment adaptation, coping) from trained health care professionals to patients with AD and their caregivers.²¹ First, providers must assess the patient's and caregivers' current experience, including understanding of the disease, the effect of AD on daily life, fears, barriers to adherence, goals, and resources.^{21,24} Patient-centered communication techniques such as active listening, empathy, encouragement, motivational interviewing, and open-ended questions are important in this stage to elicit the patient experience and set the stage for a collaborative process.^{21,23} Examples of topics to cover and questions to ask in the initial TPE visit are included in Table 1. Physicians can normalize concerns of patients and caregivers (eg, worries about steroid use, impact of the disease on daily life), which may allow patients to feel open to talking about barriers to adherence, as well as reduce burden. In the second step of the TPE process, providers develop educational objectives in collaboration with the patient and caregiver, tailored to the age of the patient (eg, to be capable of detecting a flare; to be capable of explaining AD to my friends).²⁴

The third step of the TPE process involves the transfer of skills from the provider to patients and caregivers. Important skills fall under 3 main categories: knowledge of the disease, practical skills, and relational skills.^{21,24} Patients and caregivers should have an in-depth knowledge of AD pathophysiology, how treatment works, aggravating factors, and the chronic course. The provider should address common concerns about treatment side effects, and a reasonable timeline for treatment response should also be understood. Practical skills include how to properly apply treatment (which sites, how often, how much, sequence of products), assess disease severity, and adapt the treatment plan based on severity.²⁴ Patients should also learn skills for coping with other aspects of the disease that affect QOL, such as itch and sleep disruption.²⁷ Relational skills may include knowing enough about the disease to explain it to others, as well as knowing where and how to obtain support during a flare.²⁴

It is important to involve children and adolescents in the therapeutic patient education process in order to gradually build management and coping skills over time with family support. This may include providing developmentally appropriate education about the disease and elements of treatment directly to pediatric patients, suggesting strategies to engage children and reduce anticipatory anxiety about skincare (eg, “wrapping a doll,” drawing with moisturizer on the skin, playing with toys, or listening to an audiobook during the bath), and developing techniques to help manage itching and scratching (eg, relaxation strategies, hands-on activities such as squeezing a stress ball, coloring or using fidget toys).^{20,27-29}

There are a range of educational resources and tools that may be useful in supporting patients and caregivers in learning skills for managing and coping with AD. A personalized, written eczema action plan (EAP) can help reinforce therapeutic objectives, serve as a daily reminder about AD care, and reduce confusion about stepwise treatment based on disease fluctuation.³⁰⁻³² It is beneficial for management plans to include a short-term follow-up appointment plan, and contact information for questions or support between visits (eg, email, phone).^{18,21} Use of posters, drawings, models, and metaphors (eg, “brick and mortar” or “house on fire” descriptions of AD pathophysiology) may help enhance patient understanding of the disease. Demonstrations of skincare techniques and observation of patient technique may help to identify and reduce common errors.^{21,29} Role-plays may be helpful in practicing relational skills such as answering others’ questions about the disease (eg, “AD is dry, itchy skin. It’s like an allergy, you can’t catch it”). When barriers to adherence are identified, patients and caregivers may benefit from collaborating with the health care provider to identify solutions tailored to their situation and preferences (eg, taking a bath before homework to avoid skipping baths when the child is tired, identifying the optimal choice for an emollient).²⁷ Shared decision-making around AD management could also be facilitated by the development of patient decision aids, tools developed using clinical evidence to inform patients/caregivers about multiple treatment options, including the benefits, risks, and uncertainties associated with each option.²⁵

Online resources from reliable sources may serve as cost- and time-effective tools for supplementing patient education provided by health care providers. Online video instruction about AD and its treatment has been demonstrated to improve AD clinical outcomes and skincare knowledge.^{33,34} The National Eczema Association is a reliable source of patient education materials (www.nationaleczema.org). Online teaching tools (www.opened-dermatology.com) may also be useful in tailoring teaching to the developmental level of the child.

The fourth step of the TPE process involves assessment of TPE efficacy. Examples of outcome measures may include objective clinical outcomes rated by the health care provider (eg, Eczema Area and Severity Index [EASI], Scoring of Atopic Dermatitis [SCORAD]), patient self-assessment ratings (eg, Patient-Oriented Eczema Measure [POEM], Patient-Oriented SCORAD [POSCORAD]), patient and caregiver ratings of AD-related QOL, AD knowledge questionnaires, and measures of the medico-economic impact of TPE programs, such

TABLE 2 Examples of therapeutic patient education approaches

Individual sessions
Nurse-led
Physician-led
Multidisciplinary (eg, physician, nurse, psychologist, dietitian)
Collective sessions
Lectures
Age-stratified workshops (for patients and/or caregivers)
Combination individual-collective sessions
Individual care with adjunct group education
Online video-based education

as number of days of hospitalization, work productivity, and treatment costs.^{24,35,36}

Therapeutic patient education providers, settings, and formats

TPE is always provided by health care providers, and often by an interdisciplinary team.³⁷ Visits may be significantly longer than traditional clinic appointments, allowing for intensive education and sufficient time with each provider. Most TPE programs have been established within medical centers, although health care providers can apply principles of TPE and shared decision-making in private office settings, as well as refer patients who may benefit from more intensive AD education. Communication between the education team and the patient’s other health care providers is important.³⁷

Interdisciplinary approaches to care for patients with AD recognize the interplay of biological, psychological, behavioral, and dietary factors affecting AD outcomes and QOL, as well as the wide range of knowledge, skills, and support that patients and families require to effectively manage and cope with the condition. Common members of TPE teams include physicians (dermatologists, allergists, pediatricians), nurses, psychologists, and dietitians.^{27,37} Nurse-led educational sessions allow for increased time for comprehensive patient education about skincare techniques.³⁸⁻⁴¹ Psychologists may provide support to patients and families in learning strategies to break the itch-scratch cycle (eg, relaxation training, habit reversal, stress management), improve sleep, enhance self-esteem and relational skills, and facilitate adherence to treatment plans.^{27,42,43} Dietitians provide education to promote effective management of comorbid food allergies and optimize patient growth and nutrition.^{27,42}

TPE may be provided using an individual approach, in which the patient and family meets individually with a provider or

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group of providers, such as a physician visit, nurse-led teaching session, or interdisciplinary clinic/program.³⁷ Alternatively, education may be provided in a collective format, such as a lecture or group workshop (Table 2). Typically, lectures have the capacity to reach a larger audience, while smaller workshops or “eczema schools” provide opportunities for the exchange of peer-to-peer information and support, as well as transfer of practical skills through methods such as modeling of skincare techniques, problem-solving, and role-playing. Workshops may be organized by patient age, and may be single or multiple sessions.^{37,42} Some centers have developed models that combine care provided in an individual format with group-based education.^{27,29,37,44} Most individual and collective TPE programs have been targeted towards patients with moderate to severe AD, a significant impact of the disease on QOL, and/or a history of treatment failure.³⁷

Evidence for the benefit of TPE in AD

A number of studies have examined the effectiveness of TPE in randomized clinical trials,^{38-41,45-49} with overall evidence suggesting a positive impact of TPE on outcomes such as disease severity, treatment adherence, QOL, and coping with itch.^{24,50} Studies vary in terms of interventions studied, including multi-session group workshops for adults, pediatric patients, and caregivers facilitated by multidisciplinary teams (eg, dermatologists, nurses, psychologists, dietitians), as well as nurse-led clinics and educational sessions. In several studies that did not find a significant effect of TPE on QOL, the educational component was less than 30 minutes,²⁴ highlighting the importance of comprehensive patient education. There is some evidence for the cost-effectiveness of TPE.^{45,51} However, more trials are needed to compare different program methods to standard treatment using outcomes such as treatment and prescription costs, number of days in the hospital, and indirect costs, such as missed school or lost wages.²⁴

Access to care

In addition to gaps in patient and caregiver knowledge and skills, the financial burden of AD care and the limits to access to care may place barriers on AD patients’ management of their chronic disease.⁸ TPE programs can be costly, given the resources associated with interdisciplinary care, such as professionals involved, space requirements, and program administration. Funds for TPE come from different sources, depending on the country and health care system in place. In the United States, funds for clinic visits may include payments from insurance companies for individual visits with providers, although components of care such as provider collaboration and group educational sessions may not be billable services.^{21,44} Collective sessions may be funded through patient and family donations, grants, and support through collaboration with patient organizations.³⁷ In other countries such as Germany and France, health agencies also provide funding for educational activities such as TPE.²⁴

Patients may have limited access to care with physicians such as pediatric dermatologists and allergists.^{52,53} Nurse practitioners may play an important role in the provision of TPE, with evidence suggesting comparable improvement in severity and QOL with care provided by nurse practitioners as compared with derma-

tologist-provided care, as well as greater caregiver satisfaction and cost-effectiveness with nurse-provided care.^{45,51,54} Models of collaboration between specialty and primary care can also support timely diagnosis and treatment of AD through the training of primary care physicians in AD management and patient education, providing primary care providers with management and educational resources (eg, checklists, teaching tools, QOL indexes, itch severity scales, resource books, and websites), and ensuring channels for ongoing consultation with and referrals to specialists.^{27,55} Additionally, broad integration of TPE into the medical education of physicians may help to promote improved education for patients with AD and their caregivers.²⁴ Use of the aforementioned tools, such as validated video-aided patient education and online patient resources from trusted sources, can also support increased access to educational information for patients and caregivers.^{33,34}

One of the greatest barriers to AD care is access to medications, higher out-of-pocket costs due to rising costs of treatments, limited insurance formularies, and insurer coverage requirements including prior authorizations and step-therapy requirements.⁵⁶⁻⁵⁸ Out-of-pocket costs pose a significant threat to patients’ access to care and adherence to treatment.⁵⁹ In order to increase access to medications, the National Eczema Association (NEA) has recommended practical strategies to increase access to medications, including the use of generic medications when possible due to lower cost and broader insurance coverage than for branded prescriptions; checking which topical corticosteroids are available on the patient’s formulary; as well as supporting patients’ regular and routine use of moisturizer and topical steroids given the cost-effectiveness and the requirement for step therapy prior to authorization of some systemic agents. It is also important for physicians to prescribe the appropriate amount of medication so that the patient copay is maximized. If prior authorizations are rejected, appeals can be made and a peer-to-peer conversation with a medical doctor may support medication approval. Physicians, other health care professionals, and patients can also contact their state and federal officials to advocate for the advancement and accessibility of AD treatments.

Conclusion

Providing patients and caregivers with the knowledge and skills necessary to manage and cope with their disease is an integral component of AD care. TPE and shared decision-making are promising approaches for facilitating improved adherence, disease outcomes, and QOL for patients with AD. It is important to facilitate increased access to AD care, including cost-effective and evidence-based patient and caregiver education.

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