

BEYOND CHILDHOOD ATOPIC DERMATITIS - PSYCHODERMATOLOGICAL ASPECTS

DERMATITA ATOPICĂ LA COPIL - ASPECTE PSIHODERMATOLOGICE

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Abstract

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Atopic dermatitis is a common inflammatory chronic skin condition, usually starting in early infancy and posing important physical, psychological and social distress to both children and their parents. Taking into consideration all of these aspects, the goal of psychodermatology is to teach and help patients and their families to cope with their disease, at the same time making them more adherent to traditional treatment measures. Since high standard medical care is the goal of every well trained physician, the management of childhood atopic dermatitis should consist of a multidisciplinary team of experts, including dermatologists, allergologists, pediatricians, but also psychologists or family therapists, in order to achieve best therapy results.

Rezumat

Cuvinte-cheie:

dermatita atopică la copil, impact asupra familiei, comorbidități psihologice, chestionare, genograme

Dermatita atopică, dermatoză inflamatorie cronică frecvent întâlnită în practica medicală, cu debut în copilăria timpurie, afectează la nivel psihologic și social atât pe copiii cât și pe părinții acestora. Având în vedere aceste aspecte, scopul psihodermatologiei este acela de a educa și ajuta pacienții și familiile lor să facă față afecțiunii, determinându-i în același timp să adere mai bine la opțiunile terapeutice existente. Întrucât dezideratul oricărui medic bine instruit este acela de a oferi servicii medicale de înaltă calitate, managementul DA infantile trebuie să cuprindă o echipă multidisciplinară alcătuită din dermatolog, alergolog, pediatru și, nu în ultimul rând, psihoterapeut.

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INTRODUCTION

Atopic dermatitis is a chronic and relapsing inflammatory skin disease characterized by eczematous skin lesions, xerosis, lichenification and severe pruritus⁽¹⁾, affecting both children and adults, with an important impairment on the child's and parents' quality of life and significant financial impact on the healthcare resources⁽²⁾. Approximately 60% of patients will experience remission, while others will progress through the atopic march (asthma, allergic rhinitis)⁽³⁾.

The pathogenesis of eczema is still a subject of debate, but two major models are mainly recognized: impairment of the epidermal barrier function⁽⁴⁾ due to FLG (fillagrine gene) loss-of-function mutations⁽⁵⁾ and immune function disorders⁽⁶⁾.

PSYCHOIMMUNOLOGY

Patients with AD often report a close relationship between emotional distress, pruritus, and scratching, and 81% report that psychological stress aggravates their pruritus⁽¹⁾.

In response to stress, various neuroendocrine mediators (adrenocorticotropin, B endorphin, catecholamines and cortisol) are produced. Psychological stress may also lead to a disruption of the skin barrier function and stratum corneum cohesion, as well as epidermal antimicrobial function, through a mechanism which may be related to cytokine secretion⁽⁷⁾.

QUESTIONNAIRES

Even though pruritus is the predominant complaint in atopic dermatitis patients, up to date no standard method of documenting pruritus has been established. Different scales, such as the visual analogue scale (VAS), numerical ratio scale (NRS), verbal rating scale (VRS)⁽⁸⁾, Itch Severity Scale (ISS), Eppendorf Itch Questionnaire, 5-D Itch Scale, Objective Severity Assessment of Atopic dermatitis (OSAAD), Atopic Dermatitis Quickscore (ADQ), Patient Oriented Eczema Measure (POEM), SCORing Atopic Dermatitis (SCORAD) and Eczema Area and Severity Index (EASI) have been used in studies in the attempt to document pruritus and other specific features of the disease⁽⁴²⁾, but unfortunately they do not assess the impact of atopy on the quality of life⁽⁹⁾.

Regarding the impact of atopic dermatitis on a psychological level, there is a need for quality of life (QoL) questionnaires focused on skin disorder, pediatric population and family burden. Common scales used to assess QoL in dermatological pediatric patients include skin specific questionnaires, such as Dermatology Life Quality Index (DLQI), Dermatology Quality of Life Scales (DQoLS), the Dermatology Specific Quality of Life (DSQL), Chronic Skin Disease Questionnaire, Skindex-16, Skindex-Teen⁽¹⁰⁾, Children's Dermatology Life Quality Index and ItchyQoL⁽⁹⁾.

Specific questionnaires designed for atopic dermatitis children have been recently proposed. The Childhood Atopic Dermatitis Impact Scale (CADIS), a 45 items quality of life scale, specifically designed

for children with atopic dermatitis younger than 6 years and their parents, assesses child dimensions (symptoms and activity limitation/behavior), and parent dimensions (family/social function, sleep, and emotions)⁽¹¹⁾. The Infant's Dermatitis Life Quality Index is a 10 items parent-generated QoL questionnaire focusing on dermatitis severity, sleep disturbance, family and social impairment⁽¹²⁾.

Little information is available about the effect of childhood atopic dermatitis on family function⁽¹³⁾. The Dermatitis Family Impact (DFI) questionnaire is the only disease specific measure to assess the impact of atopic eczema on the QoL of the parents and family members of affected children⁽¹⁴⁾. DFI is a 10 questions instrument revealing the impact of atopic dermatitis in areas such as housework, food preparation, leisure activities, sleep, emotions and family relations.

Recently, Balkrishnan et al (2014)⁽¹⁵⁾ have found a significant association between family impact and disease severity. Their results highlight the importance of studying the burden of caregivers, as a less burdened caregiver is potentially more likely to adhere to treatment guidelines for the child, as well as to ensure optimal availability of care for the child.

GENOGRAMS

Genograms are family tree diagrams that display a person's family relationships and medical history, over at least three generations^(16, 17), using simple symbols linked with connectors that explain how each person is related.

This tool helps to go to a complex vision of psychosomatics. This means to see the symptom as a non-verbal language trying to express psychological suffering into the family. Difficulties in verbalizing emotional experiences by psychosomatic patients come from the fact that emotions are carefully filtered to conserve a "pseudoharmony" in the family system. This "myth of unity" seems to form the cement of the family beyond which exist "fantasies of rupture", fears of family disaggregation. By constructing the genogram we discover in these families' pasts the presence of traumatic events. The theme of loss often dominates these histories and is associated with deep emotional experiences of separation anxiety. This is carried out by the parents and the child, as young as he can be. Building the genogram opens the doors to a better understanding of what is involved. It can also help to express the feelings related to this difficult past and to understand why a psychotherapeutically approach could be helpful.

Moreover, the child often functions as a bond between parents who have a dysfunctional relationship. By being ill the child binds his parents to each other when they cannot resolve their couple problems. The child becomes the mediator of communication in the parental dyad. The illness has the function to protect the parents. When they are busy with the child they have no time to look to their relationship and they can avoid the conflicts between them.

QUALITY OF LIFE (QoL) AND PSYCHOLOGICAL COMORBIDITIES

The impact of atopic dermatitis on QoL is unexpectedly high; eczema has profound negative consequences for the patient, the family and caregivers, affecting their physical, psychological and social wellbeing.

Atopic dermatitis starts in the first years of life and, because of its symptoms, it can have the ability to affect the parent-child relationship. Early relationships are important because they influence the organization of stress and emotions. Some mothers of children with AD are more depressed, hopeless and overprotective. Lack of positive nurturing during childhood may lead to disorders and behavioral problems, such as self-image issues, personality disturbances, dysthymic states and neurotic symptoms ⁽⁷⁾. Studies reveal that children with atopic dermatitis displayed more aggression towards their parents and reported more separation events in their lives. The mothers in these studies were also rather distant and showed little emotion, feeling stressed by the outward appearance of the child. In contrast, other studies point out that parents react with overprotection towards their skin-diseased child and thus inhibit the child's development. The atopic dermatitis patient is incapable of perceiving his skin as a protective, enveloping shell. Children with AD have been noted to have a less secure attachment, which can increase feelings of stigmatization. A recent published study revealed that the odds for attention deficit hyperactivity disorder was significantly increased in children with atopic dermatitis compared with control subjects ⁽¹⁸⁾.

Reduced sleep efficacy leads to tiredness, mood changes, impaired psychosocial functioning of not only pediatric patients, but also their families. Long-term studies have shown that infants with AD who exhibit signs of sleep disturbance and those who experience sleep problems are at increased risk of developing emotional and conduct problems in adolescence ⁽⁹⁾. In addition, the social interactions of such children are affected, especially at school, where they are subject of embarrassment, comments, teasing, bullying, all of these leading to social isolation, depression and school avoidance. The child's lifestyle is also limited with respect to clothing, holidays, staying with friends, owning pets, swimming and so on ⁽¹⁹⁾.

Even though the psychological impact is not directly related to the overall area affected or to the objective severity of the condition, there is evidence that suggests that being affected in visible places such as the face, hands or genital areas causes higher levels of distress ⁽²⁰⁾.

Childhood AD also affects parents, who report high levels of stress related to treating and taking care of such a child and feelings of helplessness, guilt, anger and depression ⁽¹⁹⁾ regarding the symptoms. In addition, this situation can negatively affect spousal relationships, the attention that parents give to siblings ⁽⁹⁾ and the financial

status, particularly on lower income families ⁽¹⁹⁾. Furthermore, there is growing evidence that, in atopic dermatitis, dysfunctional family dynamics may play an important role, leading to a lack of therapeutic response ⁽²¹⁾.

Although many studies focused on the negative impact of atopic dermatitis on family members' lives, many participants also described positive effects. Some family members felt closer to the patient through supporting each other in difficult times, and others described making more effort to spend time as a family. However, these positive effects did not outweigh the huge burden felt by family members, and many could not identify any positive effects ⁽²²⁾.

COPING STRATEGIES AND ADHERENCE

According to Huang-Tz Ou et al. (2010) ⁽²³⁾, poor adherence is common in children with chronic diseases and it is estimated that approximately 30% are nonadherent to treatment recommendations. In children with AD, poor adherence may be the primary reason for failure of topical corticosteroid treatment, which can lead to use of potentially toxic systemic medications; hence the importance of behavioural and educational interventions to help improve adherence. Parents are sometimes terrified of the risks of medications and time spent to reassure them on the safety of the medication can influence compliance. Giving an appointment shortly after starting a topical corticosteroid may also result in better compliance. Positive reinforcement should not be forgotten in children, and the use of a sticker chart can prove to be an easy technique to motivate children to apply the medication or stay still for Mum or Dad to apply the cream.

Coping strategies should not be forgotten and time spent talking about the difficulties and challenges that patients and families have to face on a daily basis will help adherence, clinical outcomes and quality of life. The ultimate goal should be to provide the family and the child with the skills and tools to control the symptoms. A written home-care plan detailing diagnosis, medications, treatments and psychosocial recommendations should be provided. Without a written plan, patients or caregivers may forget or confuse skin care recommendations ⁽²⁴⁾.

When a treatment is failing, ask about the possible causes and discuss them openly, trying to find solutions or alternatives. Remember to explore possible fears or inconveniences associated with the treatment. The dermatologist needs to acquire the skills in addressing these practical aspects that will improve the patient-doctor relationship and translate into better adherence and outcomes ⁽²³⁾.

PSYCHOTHERAPY

Psychological intervention can range from a short psychoeducation program to daily therapy sessions focusing on the specific needs of each family ⁽²⁴⁾.

In the four-step process of Therapeutic Patient Education (TPE), the first step is aimed at understanding what the patient already knows (believes, fears and hopes) in order to determine his/her difficulties and resources. In this first step, barriers to adherence are identified. In the second step, educational objectives are discussed and decided with the patient. The third step is about acquiring the necessary skills to achieve the objectives. All sorts of programs may be necessary in this third step. Finally, the fourth step is the assessment of the TPE⁽²⁵⁾.

Both children and families benefit from some type of psychological support, either in group format or in individual sessions. However, when there are no mental health professionals in the team to offer this support, the use of stories can prove helpful in order to explain the condition to the child, establish a correct self-perception with reference to the skin condition, try to break the itch-scratch cycle, and improve treatment adherence. The use of stories has proven to reduce stigma and increase understanding of the illness, as well as to introduce behavioral changes, facilitate education and improve self-esteem⁽²⁶⁾. The use of relaxation with imagery has also proven to be effective in children suffering of AD, as it can reduce itchiness and thus, scratching⁽²⁷⁾.

While the evidence base for managing medical treatments for AD is robust, a recent Cochrane Review update (2014)⁽²⁸⁾ reveals a dearth of evidence for interventions to meet the psychological and educational needs of parents and children with AD. This update concludes that there is a potential for health visitors and school nurses to work collaboratively with dermatologists and psychologists on future developments in psychological and educational interventions for AD.

MEASURES TO INFLUENCE THE ITCH/SCRATCH CIRCLE

The itch-scratch cycle is responsible for much of the misery and chronicity of atopic dermatitis, emotional factors can cause and frequently heighten the itching and scratching behavior, both leading to serious impairment on QoL. Negative effects of pruritus include sleep disorders, anxiety, depression, financial costs, helplessness, frustration, and suicidal thoughts⁽⁹⁾.

Minimizing scratching is usually one of the main treatment goals and the techniques used vary depending on the age of the child, but may include distraction, habit reversal, cognitive therapy, biofeedback and hypnosis⁽²⁴⁾.

As mentioned in the European Guidelines of Itch⁽²⁹⁾ evaluation of the biographical aspects in itch patients is the first step into a psychosomatic explanation of itch. Special techniques to reduce itch in AD patients are relaxation methods like Jacobsen muscle relaxation⁽³⁰⁾ and behavioral approaches of habit reversal techniques⁽³¹⁾. The habit reversal techniques were introduced into the management of chronic itch in the early 70's^(32,33) and

well established into the skin pruritus management in education programmes⁽³⁴⁾. Other aspects were developed to reinforce procedures by mothers of AD children⁽³⁵⁾.

MEASURES TO REDUCE NEGATIVE EFFECTS ON SOCIAL RELATIONSHIPS

The impairment on social relationships are well-known in AD⁽³⁶⁾ and the measures to reduce negative effects are developed but rarely proved in controlled studies. The measures which look helpful are, beside habit reversals techniques, the psychotherapy approaches with behavior therapy and psychodynamic therapies. In behavior therapy the social relationships are mostly reinforced by learning social communication with role-plays as they were used in the education programs^(34,36,37). In psychodynamic therapies the biographical aspects and learned interactions with significant others are mostly the main topics in the therapy sessions⁽³⁸⁾.

PATIENT EDUCATION PROGRAMS

Although AD is primarily a condition in small children, it affects the whole family, and education concerning the disease and its management is usually needed⁽³⁸⁾. Educational programs provide information on the disease and aim to improve patients' skills in self-management of the condition. An important aim is to improve treatment compliance and thereby improve eczema status. These programs usually include background information on the etiology, epidemiology and results of recent research on AD. Topics such as the clinical features of AD and its complications, particularly infections and exacerbating factors are approached. Emphasis should be placed on disease management, including use of moisturizers, medical treatment, and the avoidance of exacerbating factors. Stress control techniques should also be taught, as well as the principals of behavioral approaches and interventions to deal with problem behavior in children⁽³⁸⁾.

Worldwide, there is a diverse spectrum of atopic dermatitis educational programs ranging from group lecture models in Asia to individualized approaches in Canada. In Europe, such group approaches have been implemented in Germany and France. The patient education program that was tested in the German Atopic Dermatitis Intervention Study (GADIS) was found to have positive effects on disease severity, satisfaction with treatment and costs, coping behavior of children, parental management of the disease, and hospitalization rates.

The German Eczema School Program is an interdisciplinary program that has developed 10 academies in Germany with widespread workshops to train physicians to prepare AD education programs in their own medical centers^(39,40).

Taking things further, age related educational programs for the control of atopic dermatitis in children and adolescents have been developed

and proved to be significantly more effective than the conventional treatments. Therefore such programs should be considered and be introduced into routine management of atopic dermatitis in children and their parents⁽⁴¹⁾.

CONCLUSIONS

AD is one of the most common chronic inflammatory skin diseases, usually starting in early infancy, posing an important burden on both the patient and his family. This is the reason why it is extremely important for dermatologists, allergologists, pediatricians and other healthcare professionals that treat such patients to go beyond the diagnostic label and try to assess the psychological suffering in each individual case. Even in patients with a mild presentation of AD, the psychosocial and economic burden of the disease can be profound⁽⁷⁾.

The relationship between patient and healthcare provider is important especially in clinical dermatology, because psychological problems are often associated

with skin conditions. As a consequence, high-quality consultations⁽⁷⁾ consisting of multidisciplinary treatment programs should include the pediatrician, a dermatologist, and a psychologist or family therapist⁽⁹⁾.

In addition, the CALM-IT (Course of Advanced Learning for the Management of Itch) Task Force, an interdisciplinary group of experts specializing in pruritus treatment, which convened in Berlin in 2012, brought to attention a few more important aspects: the need for more integrated QoL tools that consider both the child and the family, the need to improve access to multidisciplinary treatment programs, and the need to provide rapid itch control and to develop more targeted therapies for pruritus that are safe for infants and children⁽⁹⁾.

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