

Addressing Psychosocial Aspects of Atopic Dermatitis

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KEYWORDS

• Atopic dermatitis • Behavior • Sleep disturbance
• Adherence • Quality of life • Psychology

Atopic dermatitis (AD) is a common disease estimated to affect between 5% and 15% of children and 3% of adults, often with significant psychological consequences. Onset is often during the first year of life, but the disease can occur throughout childhood and early adulthood. The severity can vary from a small irritating patch to the involvement of extensive areas of the body, with intense pruritus. The clinical course varies but can be chronic or chronic relapsing.

AD has been termed “the rash that itches,” a description suggestive of the distress that can accompany this common disease. Although distress has long been recognized, the increasing specificity of the tools used to measure components of the distress associated with AD^{1–3} and the objective measures of AD severity^{4,5} have enabled investigators to refine knowledge regarding the effect of AD. Families of patients with AD report that quality of life is affected by disease severity, lack of sleep, pruritus and scratching, and the burden of caring for the patient. Although many patients with AD and their caregivers cope well with the disease, there is an increased risk for emotional problems in patients and caregivers, and patients are at an increased risk of having difficulties in sustaining attention. AD clearly can burden and stress families, but stress in turn can affect the illness. Coping is influenced by family factors and disease-specific factors.

There have been significant advances in understanding the pathogenesis and course of AD. Many patients with mild disease are likely to experience remission; however, patients with moderate or severe disease may experience a chronic relapsing course. Although current medical science cannot cure AD, treatment can

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lessen the severity and decrease the frequency of exacerbations. The potential for improvement in the control of AD has increased the possibilities for psychosocial intervention from the limited focus on teaching families and patients how to manage the distress of AD to targeted interventions that may lead to significant gains, such as improved sleep, decreased scratching, and increased adherence with effective treatment. Efficient administration of these interventions is best undertaken within the context of a multidisciplinary team.

This review addresses the present state of knowledge regarding the psychosocial effect of AD and the potential interaction between the family's emotional resources, coping and illness. The components of successful multidisciplinary intervention are also reviewed.

EFFECT OF PEDIATRIC AD ON CHILDREN AND CAREGIVERS

Caring for a child with AD has a major effect on families across a variety of domains. Several investigators have queried children with AD, their parents, and their siblings to determine the specific areas of family life that are affected by this disease.^{1,6-8} Parents' concerns have ranged from the practical demands of daily care to sleep deprivation for all family members and the financial burden brought on by treatment costs and other special needs. Chamlin and colleagues⁹ documented the effects on 4 domains of functioning for parents and children, including physical health (sleep disruption, itching and related scratching), emotional health (fussiness in children, various emotional stresses for parents), physical functioning (activity restrictions, missed work), and social functioning (feelings of isolation, negative reactions from family members). This wide range of AD-related demands and stresses results in major emotional challenges for parents, affecting their own lives and those of their children, with more severe disease having greater effect on multiple aspects of family functioning.¹⁰

The practical demands for the daily care required by children with AD consume a great deal of time and energy. In a sample of children treated at a tertiary care center for moderate and severe AD, most parents reported spending about 3 hours each day caring for their child's skin.¹¹ Parents' care includes getting their children to take bath, accept skin care, avoid allergens and irritants, and ensuring that their child refrains from scratching.^{1,6} The difficulties posed by the itching and related scratching are typically the first to be mentioned by parents when they are asked about the effects of their child's AD on their quality of life,^{1,6} and managing scratching is the primary concern for parents requesting a pediatric psychology consult.¹² Ratings of itch intensity or pruritus, whether made by parents for young children or by older children for themselves, were significantly and inversely correlated with parents' quality of life, that is, more intense pruritus was related to lower scores for parents' psychosomatic well being, social life, emotional coping, and acceptance of the disease. Older children's self-report of itch intensity was also negatively correlated with their self-report on quality of life and positively correlated with their depressed mood and catastrophic thinking.¹³ In addition, higher ratings of child itchiness were related to poorer parent coping with AD, with more aggression related to child scratching, protective behavior, control of scratching, and negative treatment experience.¹³ These responses are consistent, with itching skin being the focal experience of AD and the management of itching being the primary coping requirement.¹

Increased itchiness in children during the night is associated with difficulties in sleeping. Because parents are often up trying to comfort their children and prevent scratching, nighttime sleep deprivation and daytime exhaustion for parents is

common, severely affecting their quality of life.^{1,14} A study conducted in the United Kingdom investigated the risk factors for AD severity and its effect on quality of life for children aged 5 to 10 years.¹⁵ The investigators found that the most severe effect was sleep disruption in the parents and siblings of the child with AD. Moore and colleagues¹⁶ conducted a comparative questionnaire study of children with AD aged up to 16 years and parents of children the same age with asthma. Results showed that for 2 nights prior to completing the questionnaire, mothers were up for an average of 39 minutes per night and fathers were up for 45 minutes per night; in comparison, parents of children with asthma lost no sleep at all. The time for which mothers were up correlated with their child's age and parent-reported severity of the child's AD. Depression for the mothers of children with AD was 2-fold higher than that for the mothers of children with asthma. Follow-up analyses showed that the mothers' depression scores were related to their sleep disruption rather than to the severity of their child's AD.

Although parents report tremendous effects of their child's AD on their quality of life, research has been mixed as to whether parents' overall psychological functioning is affected. In a study of parents of school-aged children with AD, maternal mental distress was not increased, although parents described themselves as anxious and overprotective.¹⁷ In contrast, in a study of parents of young children with AD, attending an inpatient rehabilitation clinic, high rates of psychological distress were observed in the parents.¹⁸ On the mental health scale of the 12-Item Short Form Health Survey (SF-12®), 39% of the mothers scored greater than a standard deviation less than mean normal values and 15% scored more than 2 SDs less than the healthy norms. Psychosocial distress was the highest for mothers of children with the most severe disease.

In addition to being stressed by demands on their time and exhausted by sleep deprivation, parents report a myriad of anxieties and worries about their children's emotional and behavioral functioning and about how children are coping with their AD. Parents worry about their child's absence at school, attention to academic tasks, and disrupted peer relations.¹ Parents are concerned about their children's behavioral and mood changes and the effects of AD on their children's self-esteem. Parents also express concern about how their child's AD is affecting their relationship with their child, as well as their parenting. Among the parents of preschoolers with AD, mothers felt more stressed in relation to their parenting and less efficient in their disciplining of the affected child, and these mothers had less social support than the mothers of unaffected children.¹⁹ In spite of these worries, the mothers did not display negative attitudes toward their children with AD, and there was no difference in their attachment security between children with AD and normal children. Nevertheless, parents' worries about their children's psychological adjustment are an important source of emotional distress for caregivers of children with AD.

Concerns about financial costs associated with having a child with AD have been noted consistently in response to quality-of-life queries.^{1,20} Direct financial costs are derived from purchase of medications and emollients and special foods and supplies, as well as costs related to physician and clinic visits.²¹ In addition, indirect costs accrue from the need for parents to take days off from work or because a parent elects not to work to care for the child with AD.^{19,21} The rankings of the importance of financial burden relative to other concerns vary by study. For example, financial burdens were the least-frequent concern of families from the United States, responding to the Dermatitis Family Impact (DFI) questionnaire in the 1990s,¹ whereas other researchers reported that according to DFI responses, the greatest effect on the family was on the domains assessing treatment costs.¹⁴ Although the financial burden of AD

is very high for the society as a whole,²² the financial effect for individual families likely depends on factors such as their country, their health care system, and family resources.

ADULT AD

Although less prevalent than pediatric AD, adults who are affected by AD also report negative effects on their quality of life. For example, adults with AD report lower physical role, social functioning, and vitality than adults with psoriasis.²³ Adults with AD report feeling frustrated with their disease and embarrassed and angry about their appearance.²⁴

THE RELATIONSHIP BETWEEN AD AND PSYCHOLOGICAL DISORDERS

Although clinical observation and research evidence indicate that psychological distress is increased in patients with AD and in parents of children with AD, it is unclear whether the incidence of actual psychological disorders is increased in this group and, if so, what would be the direction of causality. A single causal direction is often assumed in the relationship between psychological distress and AD, in which the disease is presumed to introduce distress into the life of the patients, driving quality of life downward and psychological dysfunction upward. More probable is a 2-way relationship in which the disease and psychological status are interactive.

AD is clearly a difficult disease for patients and families.^{23,25–29} However, results from quality-of-life surveys leave other questions unanswered, such as does feeling distressed by one's disease mean that a psychological disorder is present? Attempts to identify an AD personality trait have generally been unsuccessful; however, increased anxious^{24,25,30–33} and depressive symptoms^{24,33} have been identified in groups of patients with AD. Elevated symptom scores do not invariably translate into a clear behavioral or mood disorder; rather, the signs of distress falling short of psychopathology characterize many patients with AD.^{34,35} A questionnaire study on 108 patients with AD, psoriasis, and severe acne found small but significant differences between these patients and controls, leading to the conclusion that most were experiencing minor psychological distress but that rates of depression and anxiety were not increased.³⁵ A Canadian survey of 480 patients with facial acne, alopecia areata, AD, and psoriasis reported that suicidal ideation rates were higher in patients with psoriasis and acne when compared with general medical patients (5.6%–7.2% vs 2.4%–3.3%) but not significantly elevated in those with AD,³⁶ suggesting again that in most cases, psychological distress secondary to the skin disease does not result in clinical psychopathology. At the most-severe end of the AD spectrum, clinical depression and anxiety may be increased, although documentation of a severity-mediated relationship between disease and psychological outcome is scant.²⁵ In one study 45 patients with AD and 34 health controls completed psychological questionnaires. Patients with disease that was rated as mild demonstrated no increase in test scores, reflecting anxious and depressive symptoms. However, patients with moderate and severe disease demonstrated increased psychological symptoms relative to controls.²⁵ In another study from Japan, suicidal ideation was reported in 0.21% of patients with mild AD, 6% with moderate disease, and 19.6% with severe disease.³⁷

The association between psychological distress and AD does not establish a causal relationship. Intuitively, the increased psychological distress brought on the patient by this disease would seem to account for any increase in distress symptoms. However, at the same time, patients with psychological distress from causes other than their

skin disease may experience an exacerbation of their AD. Distressed patients may have increased vulnerability of developing AD or experiencing an exacerbation in their skin condition. Stressful events have often been observed to occur before worsening of symptoms of AD.^{38–40} In a study, an AD exacerbation followed a stressful day by 24 hours.³⁹ One theory emerging from studies of AD and stress posits that adrenocortical response to stress in children with AD is attenuated compared with health controls.⁴¹ Laboratory studies from this research group suggest that patients with AD are more susceptible to stress-induced skin eruptions because of the hyporesponsive hypothalamic-pituitary-adrenal axis that blunts the body's natural ability to produce cortisol and suppresses inflammation in response to stress^{42,43} or, alternatively, because of increased reactivity in the sympathetic adrenomedullary system.⁴⁴ One study found that in addition to stress increasing the severity of AD, young children with AD who experienced stress were at an increased risk of developing asthma.⁴⁵

Another pathway that might explain the relationship between psychological distress and AD exacerbation addresses the role of treatment adherence. In this case, psychological distress may undermine treatment adherence, and hence may lead to poorer disease control. Depression has been repeatedly associated with declining adherence to treatments for chronic illness.^{46–50} The presence of depression in adults with asthma was associated with an 11-fold increase in the odds of nonadherence relative to asthmatic patients without depression.⁴⁹ Possibly, because adherence declines as depression increases, depression is associated with a poor prognosis in chronic medical conditions,⁵¹ and in asthma, depression has been specifically linked with increased stay in emergency rooms, hospitalizations, and unscheduled office visits.^{52–54}

Nonadherence is also a problem in the treatment of AD. A study of 37 patients with AD included adherence monitoring, using an electronic monitor that recorded each time the medication container was opened.⁵⁵ During the 8 weeks of treatment, patients used only 37% of the prescribed doses of their topical antiinflammatory medication. In a similar but smaller study, adherence was monitored in 6 patients with AD.⁵⁶ Over a period of 4 weeks, electronic monitoring revealed adherence to topical antiinflammatory medications to be averaging approximately to 50% (range 18%–100%), whereas patients reported approximately 80% adherence (range 71%–100%). Although evidence of a relationship between depressive symptoms and nonadherence in patients with AD is not available, it remains plausible that in this population of patients, as in patients with other chronic illnesses, such a relationship exists and helps to explain the relationship between psychological distress and poor disease outcomes. Because these studies involved children, this relationship may be more complex and involve the emotional state of the parent as well. In support of this result, a study that used parent-reported measures of disease management for AD found that parental mental health, family situation, and disease severity all influenced disease management.¹⁸

In summary, research data to date support the conclusion that AD decreases quality of life and increases psychological distress, although the incidence of psychological disorders in this population is not likely increased except in those with severe disease. The relationship between psychological distress and AD is most probably interactive; although the presence of AD increases the possibility of psychological distress, the presence of psychological distress also likely causes disease exacerbation either through stress-induced physiologic changes or through declining treatment adherence. Further research is needed to help clarify these relationships. Many of the studies addressing the relationship between AD and psychological functioning have been hampered by several methodological shortcomings, including (1) absence of control subjects; (2) inclusion of control subjects not well matched to index subjects

on characteristics that can influence psychological functioning, including age and socioeconomic status; (3) reliance on published normative data from questionnaire development studies rather than a matched control group; and (4) failure to acknowledge that paper-and-pencil questionnaires cannot reliably diagnose psychological disorders and that elevated scores in 1 group does not always indicate psychopathology. Increased understanding of the relationship between AD and psychological functioning will emerge from additional studies that successfully overcome these shortcomings.

THE RELATIONSHIP BETWEEN AD AND SLEEP

Patients with AD are clearly at risk for disturbed sleep. Disturbed sleep is frequently reported by parents of children with AD²⁰ and adult patients, and it has also been shown using objective measures such as polysomnography.²⁷ Although as a group, patients with AD correctly note that they are sleeping poorly, at least 2 studies have shown that self-reported measures of sleep quality do not correlate with objective measures of sleep for adults with AD.^{27,57} Similarly, a study comparing subjective report of sleep difficulty with objective signs of AD severity in children found no correlation.⁵⁸ Scratching during sleep has been measured using actigraphy^{57,59} and infrared video monitoring⁶⁰ and is associated with disturbed sleep, but scratching may not account for the whole of sleep disturbance that is associated with AD.⁶¹ Regardless of the cause, sleep disturbance affects not only the quality of life but also the cognitive function and behavior. In children who do not have AD, poor sleep has been associated with increased behavioral problems at home⁶² and at school⁶³ and poor attention span.⁶⁴ The relationship between sleep and attention-deficit/hyperactivity disorder (ADHD) for children with AD was examined in a large population-based study.⁶⁵ Children with AD were compared with age-sex-matched controls without AD. Children with AD were at increased risk of being diagnosed with ADHD only if they also had a sleep disturbance.

AD AND COMORBID ATOPIC ILLNESS

Studies that have examined the psychosocial effect of AD have either used populations without comorbid atopic illness or have not described the extent of the comorbid illness in the population studied. A significant number of children with AD may also have asthma and allergies.⁶⁶ Approximately 40% of children with AD may have food allergies (see also the article by Caubet and Eigenmann elsewhere in this issue for further exploration of this topic).⁶⁷ There is substantial literature regarding the negative effect of asthma and food allergies on quality of life, and comorbid illness may increase the negative effect of AD. However, the potentiated effect of AD on the quality of life, behavioral and emotional health of children, and families in the presence of comorbid atopic illness remains to be sufficiently studied.

INTERVENTION

Treatment of AD is complex, with education being a key component. There is evidence to support brief multidisciplinary education of parents and children with AD⁶⁸ as well as longer interventions. In a large multicenter trial for children with AD, over 900 patients, aged 3 months to 18 years, were randomized to either a wait group or a 6 week intervention group with weekly 2 hour education sessions.⁶⁹ A pediatrician provided general information about AD, daily skin care, recognition and avoidance of triggers, and unconventional therapies. A nutritionist covered topics on food

allergies, nutrition, and diet; a psychologist taught relaxation, coping, self-management, and dealing with itching, scratching, and sleep. Children were divided into 3 groups: younger than 7 years (only parents attended the groups), 8 to 12 years (parents and children attended), and 13 to 18 years (only the youth attended the groups). At 12-months follow-up, children of all ages in the intervention groups showed improvements in AD severity compared with the control group, and parents of children aged 3 months to 7 years showed improvements in quality of life on all dimensions, whereas parents of children aged 8 to 12 years showed improvements in emotional coping and confidence in medical team. Children also showed some improvements in coping with scratching.⁶⁹ Another randomized study used a similar intervention in a sample of 204 families of children with AD (aged 5 months–12 years) and found improvements in treatment adherence and treatment costs in the intervention group compared with the control group.⁷⁰

These education sessions were provided on an outpatient basis to children with moderate to severe AD. Another treatment model is to incorporate multidisciplinary care within a day treatment program for children who have failed outpatient care. Opportunities exist to expand treatment targets and expand the model of service delivery within this setting. The multidisciplinary team consists of allergist-immunologists, nurses, child life professionals, creative arts therapists, social workers, pediatric psychologists, and child and adolescent psychiatrists. Within this setting, the improvement is often dramatic,⁷¹ and families often accept and engage in multidisciplinary intervention. The ultimate goal of multidisciplinary care for children with AD is to give the family and the child tools to control symptoms at home and to improve the child's future quality of life. A study of 50 children with AD found that parents reported sustained improvements in both symptoms of AD and quality of life over the course of 2 years after treatment at the authors' center.⁷² In this setting, patients receive a comprehensive evaluation, treatment, and education over 5 to 10 days. Caregivers are taught skin care and hydration therapy (baths and wet wraps) within the context of treatment; they initially observe the nurse provide care and then perform the care themselves with the guided supervision of experienced nursing staff (see the article by Nicol and Ersser elsewhere in this issue for further exploration of this issue).

Child life professionals and creative arts therapists use developmentally appropriate tools to help the child cope with procedures and minimize psychological trauma. The child life specialists help the child through the first few baths, which can be uncomfortable and anxiety provoking, by using techniques such as gently engaging and distracting the child. Each child is given their own set of bath toys to take home, and child life professionals model for parents in how to engage children in distracting activities while remaining calm. The creative arts specialist runs a daily group focused on acclimating children to their treatment and helping them understand their feelings about themselves and their illness. Techniques include giving the child a doll, which they are told shares their likes, dislikes, and illness.⁷¹ The child decorates the doll and marks the regions of the skin affected by AD. The child is asked to help the doll feel safe and help the doll's skin get better. The child gives the doll a symbolic bath, applies ointments, and wraps the affected regions. Children often act more protectively and caringly toward their doll than they have been able to toward themselves. Parents attend a daily discussion session led by either a social worker or a psychologist. The topics include interacting with systems such as the schools and medical systems, managing outside activities, siblings, parenting, sleep, and breaking the itch-scratch cycle. Parents benefit from interacting with other parents who share some of their challenges.

Each patient (and family unit) is assigned a psychosocial clinician (social worker or pediatric psychologist) on arrival, who performs a behavioral health assessment of the family's and child's coping and response to illness. Treatment is then tailored to the needs of the family and varies from supportive psychoeducational care to more intensive daily therapy focused on marital issues, anger, guilt, and so forth. Minimizing scratching is a treatment goal that the child is able to engage in more readily because their AD typically improves within 48 to 72 hours. Techniques include distraction, replacement, biofeedback, and hypnosis, depending on the age and psychology of the child. The psychosocial clinician communicates any recommendations for further action or mental health care to the family and referring physician within a written home-care plan and any recommendations for school accommodations to the family and the school within a written school care plan.⁷¹

The psychiatrist is available for consultations. Questions typically concern sleep, diagnostic considerations and treatment options for anxiety, irritability, poor focus, and depression. Medications to help with sleep are often needed for the first few days but can often be rapidly tapered as the skin improves.⁷³ As sleep, skin inflammation, and scratching improve, the child often demonstrates a dramatic change in affect. For this reason consultations regarding mood and behavior are often held until later in the admission. Another consultation question concerns sedation for the first baths, which can be very uncomfortable and anxiety provoking. The authors recommend avoiding sedation, given proper nursing and psychosocial support for baths, because children rapidly acclimatize without sedation and the authors do not want to inadvertently communicate to the family and child that they will not be able to manage severe AD exacerbations at home.

The medical and psychosocial teams meet weekly to discuss each patient, their response to treatment, plan further care, and strategize regarding any problems. This meeting helps to ensure that families receive a consistent message from the

Box 1

Key points regarding psychosocial care

1. Moderate to severe AD negatively affects patients and their families.

2. Pruritus, scratching, and sleep problems are common complaints linked to impaired quality of life.

3. Treatment is complex and nonadherence rates are high.

4. Multidisciplinary interventions have shown success in improving treatment adherence, quality of life, and disease severity.

5. Families and patients should demonstrate skin care techniques because this often reveals problems in their understanding of AD management.

6. Managing distress around procedures is an important element of treatment that can usually be achieved without sedation.

7. Within a treatment setting, assessing psychopathology such as depression, anxiety, and ADHD is best undertaken after treatment of AD begins and acute inflammation is decreased.

8. Children can engage in managing scratching when they are not suffering from an acute exacerbation, but during an exacerbation, treatment should first focus on improving AD.

9. Sleep medication may be needed during an exacerbation.

10. Written home care plans for treatment of varying levels of severity of AD are helpful for families, and for the child who attends school, a school care plan should be included.

entire team and prevents miscommunication and more serious problems such as splitting. The team also meets with the family to review progress and address any issues. At discharge key members from the team attend a formal meeting with the family to present and discuss the written home care plan and address final questions.

SUMMARY

AD, especially moderate to severe, can have significant negative effect on patients and their families. Although this illness does not typically cause psychological disorders, it is highly distressing for children, parents, and adults. Successful treatment includes assessing and treating AD and engaging families in the complex care needed to manage illness. Evidence supports multidisciplinary intervention aimed at empowering families because they take on the many tasks associated with chronic illness. Successful teams are able to ally with patients and families to build a realistic shared optimism for the future (**Box 1**).

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