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Quality-of-life Outcomes and Measurement in Childhood Atopic Dermatitis

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Atopic dermatitis (AD) is the most common skin disease in children, affecting 7% to 17% of children in the United States.¹ Most children with AD develop the disease in the first 5 years of life, a critical time for physical and psychosocial development (see also the article by Jonathan M. Spergel elsewhere in this issue for further exploration of this topic). For example, children establish behavior and sleep patterns early in life, and AD may disrupt the establishment of normal sleep patterns, behavior, and relationships. Such physiologic and psychological effects, which not only change the life of the affected child but also affect the physical, social, and emotional functioning of parents, have been reported in young children with AD.² Several quality-of-life instruments have been developed to quantify this multidimensional effect on children and their families.^{3–11} Such measures of the burden of AD can be used to improve the lives of afflicted children and their families.

BEHAVIOR AND EMOTIONS IN AD

AD affects the emotions and behavior of children, and these effects differ with the age of the child. Reported emotional symptoms for the young child with AD include irritability, fussiness, and increased crying, and parents most often attribute these emotions to the symptom of pruritus.² In addition, parents of young children with AD describe their children as being more clingy, fearful, frustrated, and wanting to be held more.^{2,12} Several studies have documented increasing psychological disturbances with increasing disease severity (see also the article by Kelsay and colleagues elsewhere in this issue for further exploration of this topic).^{12,13}

Increased behavior and discipline problems have been documented and are increased in young children with AD, including excessive dependency, hyperactivity, restlessness, and scratching to get attention. Despite this increase, few studies have formally evaluated children with AD for attention-deficit/hyperactivity disorder (ADHD).^{14–17} One report documented increased attention problems, disruptive behaviors, restlessness, and emotional

sensitivity in children with AD.¹⁴ More recently, a population-based study was published comparing the prevalence of ADHD in children with AD with a control group. A significant association between ADHD and AD was found.¹⁷

Few studies describe the emotional effects of AD on adolescents. Adolescence is a critical time for the development of self-identity and self-esteem,¹⁸ and looking different as a result of skin disease can adversely affect teenagers during this important developmental stage. Adolescents and adults with acne vulgaris report increased anxiety, embarrassment, interpersonal difficulties, social isolation, shame, and self-consciousness, and adolescents affected by AD likely have similar or greater emotional effects because of their skin disease.^{18–20} During validation, Skindexteen, a 21-item quality-of-life scale specifically for adolescents with skin disease, was administered to 205 participants aged 12 to 18 years, 33 of whom had AD. The mean score for the group with AD was higher (indicating greater quality-of-life impairment) than the mean score for the groups with all other skin diseases (Aimee Smidt, MD, Albuquerque, NM, personal communication, October 9, 2009).

SLEEP, ITCH, AND AD

Although up to 30% of children experience sleep difficulties in the first few years of life,²¹ sleep abnormalities are more prevalent in children with AD. Documented sleep dysfunctions include delayed onset of sleep, multiple awakenings, and an overall reduced sleep efficiency.^{22–26} Sleep disturbance from pruritus and the subsequent reduced sleep efficiency often affects daytime behavior and productivity for the affected children.²² Sleep abnormalities in school-aged children with AD have been studied with home polysomnography, a recording of overnight sleep physiology. Poly-somnography revealed frequent awakenings associated with scratching episodes and an overall reduced sleep efficiency.²⁵ Awakenings persist for many children during disease remission and are often unassociated with scratching.²⁴ The cause of awakenings during disease remission is not known, but it is hypothesized that the sleep abnormality induced by pruritus may become a learned sleep pattern. Children with AD may associate sleep with itching, and scratching behavior may influence the development of an abnormal chronic behavior-based sleep pattern with frequent awakenings (see also the article by Kelsay and colleagues elsewhere in this issue for further exploration of this topic).

Sleep problems from any cause in infancy and early childhood have consequences, including greater difficulty awakening, daytime tiredness, and irritability, and may even be associated with a higher rate of ADHD.²⁷ Moreover, children with AD have documented difficulty falling asleep and night waking, which correlate with daytime behavior and discipline problems.²² Daytime sleepiness is difficult to evaluate, and children with chronic sleep loss are often mistakenly misdiagnosed with behavioral abnormalities and learning disabilities.^{22,26} Further work is needed on the cause-and-effect relationship of sleep abnormalities and behavioral issues in children with AD.

Cosleeping or bed sharing is a strategy documented in the parents of children with AD likely adopted to improve the sleep of their children, but cosleeping often leads to sleep deprivation for one or both parents.^{2,28} Although cosleeping is common (12.8% in the United States²⁹ and even more prevalent in many cultures³⁰) this sleep behavior is increased to 30% in families of young children with AD in the United States.²⁸ Parents of children with AD report bringing the child into their bed to prevent awakenings, and holding their child's hands to prevent scratching. This practice likely decreases the quality of the parents' sleep, leading to parental sleep deprivation and exhaustion.²³ If cosleeping behavior becomes habitual for children and their families, this practice may perpetuate the child's sleep disturbance beyond the time of disease flare. Sleep disturbances and cosleeping in

children with AD and their parents are directly associated with severity of AD, and likely correlate with overall decreased quality of life.²⁸

THE EFFECT OF AD ON THE FAMILY

In addition to the effects on the child, childhood AD can affect the emotional, financial, physical, and social well-being of parents.^{31,32} Mothers of young children with AD report poor social support, decreased employment outside the home, stress about parenting, and difficulty with discipline.¹² In addition, increased AD disease severity is strongly associated with a greater effect on the family, which decreases as disease severity lessens, highlighting the importance of understanding and measuring the burden of disease on the entire family.^{33–36} The effect on the family is increased when parents perceive high disease severity, worry about payment for medical care, and seek nonmedical or over-the-counter products therapy.³² It is not uncommon for parents of a child with AD to change their lifestyle and home environment dramatically to help cope with the needs of their atopic child. These changes may be financially burdensome and stressful and include changes in their homes (flooring, heating, and air-conditioning systems), vacations, and activities. In addition, parents complain of exhaustion and fatigue, likely as a result of sleep deprivation.

Parent sleep deprivation can be notable, and the mean sleep loss was quantified in one study as 1.9 hours and 1.5 hours for the severe and moderate disease groups, respectively.³⁷ Another study noted 39 minutes of sleep loss for mothers and 45 minutes of loss for fathers, and severity of sleep disturbance was correlated with maternal anxiety and depression.³⁸ Parents of children with AD have many worries, including triggers for disease flares (ie, diet and environment), the cause of disease, costs of care, proper use of medications, and long-term outcomes for their child's health, well-being, and self-esteem.² In addition, parents commonly worry about and fear the use and side effects of topical corticosteroids. In a questionnaire-based study, 72.5% participants worried about using topical steroids on their own or their child's skin. This worry led to noncompliance in 24% of individuals.³⁹ In the International Study of Life with Atopic Eczema (ISOLATE), patients and caregivers reported delaying use of topical steroids for approximately 1 week after onset of a flare.⁴⁰ This study highlights parental response to fear of medication use, with suboptimal adherence, undertreatment of disease, and the desire to seek alternative therapies, some of which may be unproven, unbeneficial, or harmful.

Parents also report significant emotional effects, including sadness, crying, guilt, and self-blame, as a result of having a child with AD. They may blame themselves because they had or have atopic disease, or they may blame their atopic spouse for their child's illness. Parents often feel responsible for exposing their children to food or environmental allergens that they believe cause or worsen the dermatitis. In addition, negative reactions of friends, relatives, and the public can be emotionally stressful for parents and often evoke feelings of anger, sadness, helplessness, embarrassment, frustration, and disappointment. Moreover, parents report accusations of child abuse or neglect from strangers and the offering of unsolicited advice as a common occurrence. To avoid such conflict, parents of children with AD may stay home more to avoid these negative interactions and thus may develop feeling of social isolation.²

MEASURING QUALITY-OF-LIFE AND EFFECT OF AD ON THE FAMILY

Quality of life is defined broadly as an individual's well-being. More precisely, health-related quality of life is an outcome that extends beyond traditional views of mortality and morbidity and includes the health dimensions of symptoms, the functional effect of disease, and the broad psychological, social, and emotional effect of disease.⁴¹ For pediatric patients, quality of life is relevant for the affected child as well as the parents and siblings. To

measure quality of life in young children and infants, parents are often asked to answer questions as a proxy for their children.

Quality-of-life measurement scales for use in pediatrics are generic or disease specific and many are age specific. Each type has a different application. For example, generic instruments are useful for comparing the effects of different diseases on children. Such a comparison was made using a generic instrument, the family questionnaire of Stein and Reissman, to compare the effect on the family of childhood AD with juvenile-onset diabetes mellitus. The investigators reported that families of children with moderate to severe AD were affected to a greater degree compared with families of diabetic children.³⁷ The lack of support for families struggling with AD compared with the support offered to families of diabetic children was suggested as a possible explanation. Another study used the Children's Life Quality Index, a skin disease-specific scale, to compare children with skin disease including AD with other childhood diseases. The greatest effect measured was for cerebral palsy followed by generalized AD, renal disease, and cystic fibrosis.⁴²

A few skin-specific quality-of-life scales have been developed for children and teenagers with skin disease. One such measure is the Children's Dermatology Life Quality Index (CDLQI), which was developed to measure the effects of skin disease on children from 3 to 16 years of age. With the initial validation of this scale, the greatest quality-of-life effects were on children with scabies and eczema.³ This finding intuitively makes sense, with diseases with greater symptomatology (itch in both cases) having a higher effect on quality of life. A more recent study using the CDLQI reported the greatest quality-of-life effect on children with psoriasis, generalized eczema, and urticaria.⁴² A cartoon version and several foreign-language translations of the CDLQI have been developed and published.⁶

When the secondary effect of skin disease, the family effect, is used to compare the effect of different diseases similar results are reported. The Family Dermatology Life Quality Index, another skin disease-specific scale, was used to compare the effect of different skin diseases on families. The greatest effect was seen with inflammatory skin disease and more specifically with eczema, psoriasis, and acne than all other skin diseases.⁹

Disease-specific quality-of-life scales for children with AD have been developed and are used as more sensitive and comprehensive measures of the specific effects of the disease. Disease-specific quality-of-life measures for children with AD include the Dermatitis Family Impact questionnaire (DFI),⁴ the Infants' Dermatitis Quality of Life Index (IDQOL),⁵ the Childhood Atopic Dermatitis Impact Scale (CADIS),⁷ the Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD),⁸ the Childhood Impact of Atopic Dermatitis,¹⁰ and the Quality of Life in Primary Caregivers of Children with Atopic Dermatitis.¹¹ The reliability and validity for most of these instruments have been evaluated and published. Measurement of quality of life with these scales has been performed primarily in clinical research, including pharmaceutical trials, but their usefulness has not been shown in daily and routine clinical practice. Each scale may be advantageous in different situations. For example, the brief 10-item DFI and IDQOL measure primarily symptoms and functioning and can be completed in a few minutes.^{4,5} The longer 45-item CADIS and 28-item PIQoL-AD weigh the emotional effects of disease more heavily, but take longer to complete.^{7,8}

DECREASING THE BURDEN OF DISEASE

It is likely that existing systems of care for children with AD are not adequate to support the emotional and social needs of many children with AD and their families.³⁷ Because of the multifaceted nature of the disease and its effects on patients and their families, support groups, detailed educational sessions, and specialty clinics are feasible methods to improve

quality of life in this population.^{33–36} However, some families and children with severe psychosocial dysfunction may require additional care such as professional psychiatric intervention.

Although support groups for pediatric patients and their families are believed to be beneficial, few data support this widely held belief.^{43–46} Support groups may help families develop positive coping strategies, increase compliance with treatment, and diminish feelings of isolation, and many practitioners recognize these unproven benefits. The National Eczema Association is one such support group for patients with AD and their families (<http://www.nationaleczema.org>). One published study examined the effects of support groups and education on children with AD and their families using the CDLQI and an itch scale. The CDLQI scores in the intervention group significantly improved in this preliminary study, suggesting a positive role for disease-specific support groups and education.⁴⁷

In addition to support groups, structured education, and specialty care from AD specialists, including dermatologists, pediatric dermatologists, allergist-immunologists, and dermatology nurses, may decrease the burden of disease and improve quality of life for children with AD and their parents.^{48–57} Nurse educators may play a critical role in this process. For example, most parents are never shown how to apply topical treatments and most often apply less than indicated and less frequently than prescribed. Following repeated education and demonstration of application of topical steroids and emollients, disease severity dramatically decreased in a study of 51 children with poorly controlled AD.⁴⁸ Another study reported a decreased effect on the family when care was received from a dermatologist in an academic medical center.⁴⁹ In addition, satisfaction with care may even be increased when a specialized nurse practitioner is involved in the education and management.⁵³

Although access to AD specialists and financial support for nurse practitioners and educators may be limited, specialty care and intensive education may ultimately be cost effective in children with moderate and severe AD.

SUMMARY

AD often affects the emotional and psychosocial functioning of afflicted children and their families. Children and families must cope with the physical symptoms, complex emotional effects, lifestyle changes, and social limitations imposed by this disease. Not only is treatment of the dermatitis indicated, but if childhood behavioral, emotional, or sleep abnormalities are noted, these should be addressed early, when intervention may be more effective. The effect on the family can be measured and most often improves as disease severity improves. Improved education and support for children with AD and their families may improve quality of life.

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