



Patients with skin diseases experience a wide range of symptoms ranging from trivial problems to major handicaps which affect their lives

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The Impact of Atopic Dermatitis on Quality of Life by C. Lifschitz

Key insights

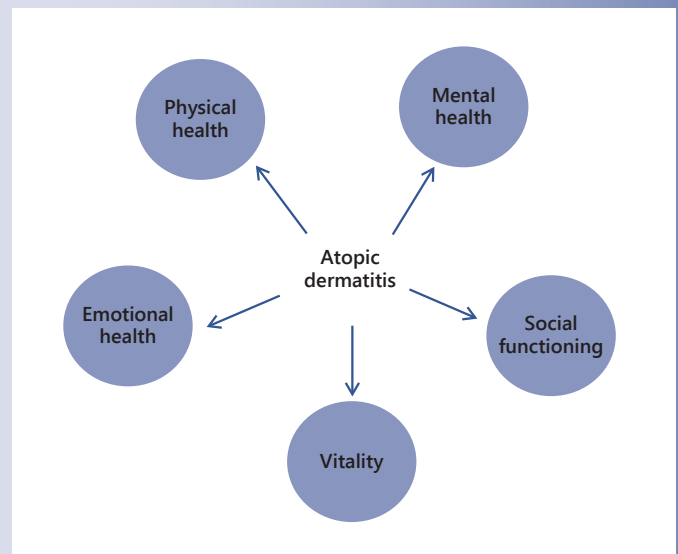
Since atopic dermatitis is one of the most common chronic relapsing childhood dermatoses, it has major social and financial implications for individuals, health-care providers, and society as a whole. Despite the prevalence of atopic dermatitis, relatively little attention has been given to the impact of treatment on quality of life. The assessment of disease-related quality of life is important because it complements the traditional clinical scoring systems and captures the effects of the disease on patients and their families.

Current knowledge

Atopic dermatitis has a large impact on quality of life, regardless of the age of the patient. Patients with the disease have inferior scores not only on symptoms, but also on social functioning and mental health. The severity of pediatric atopic dermatitis also has a significant negative impact on the physical and mental health of the families of these infants, particularly the mothers. If properly managed, the disease symptoms can be kept under control and patients are able to lead normal lives.

Practical implications

Health-related quality of life assessments not only evaluate qualities directly related to the disease, but also those that are indirectly related to the disease but that may be affected by it. The latter are often neglected by disease severity indexes. It is important to note that the instruments designed to measure quality of life usually assess patients' current experiences and are not designed to assess the long-term impact of disease,



Atopic dermatitis affects all aspects of quality of life.

which may change over time. Treating physicians should include a quality of life assessment as part of the treatment and follow-up for children with atopic dermatitis.

Recommended reading

McKenna SP, Doward AC: Quality of life of children with atopic dermatitis and their families. *Curr Opin Allergy Clin Immunol* 2008;8:228–231.

The Impact of Atopic Dermatitis on Quality of Life

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Key Messages

- Atopic dermatitis (AD) is a chronic disease. Because it affects the skin and produces itching, the quality of life (QoL) of the patient and family can be affected.
- AD has an impact on health-related QoL, particularly on social functioning and psychological well-being.
- Treating physicians should include QoL assessment when managing children affected by AD.

Key Words

Atopic dermatitis · Quality of life · Health-related quality of life

Abstract

Approximately 5–20% of children worldwide suffer from atopic dermatitis (AD), a kind of dermatitis characterized as an inflammatory, relapsing, noncontagious and itchy skin disorder. Children often develop AD during their first year of life. An increased rate of sensitization to both food and aeroallergens has been shown to coexist in patients with AD. Sensitization to well-known allergens such as cow's milk protein can occur on average in 50% of children with AD. In gen-

eral, quality of life (QoL) is perceived as the quality of an individual's daily life, that is, an assessment of their well-being or lack thereof. QoL is a broad concept that includes such things as standard of living, community, and family life. Patients with skin diseases experience a wide range of symptoms ranging from trivial problems to major handicaps which affect their lives. The misery of living with AD cannot be overstated for it may have a profoundly negative effect on the health-related QoL of children and their families in many cases. Physicians taking care of children with AD should consult parents on how their child's illness has impacted their lifestyle and recommend professional intervention if deemed necessary.

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Introduction

Atopic dermatitis (AD), also known as atopic eczema or simply eczema, is a kind of dermatitis characterized as an inflammatory, relapsing, noncontagious and itchy skin disorder. Children often develop AD during their first year of life. The disease is characterized by the presence of dry and scaly patches on the skin of the scalp, forehead, and face, particularly the cheeks, flexor surfaces of arms, torso, etc. (table 1). AD is often very itchy. Infants

Table 1. Skin manifestations found in AD

<ul style="list-style-type: none">- Atopic pleat (Dennie-Morgan fold) – an extra fold of skin that occurs under the eye- Cheilitis – inflammation of the skin on and surrounding the lips- Hyperlinear palms – palms with an increased number of skin creases- Hyperpigmented eyelids- Ichthyosis – skin with dry, rectangular scales- Keratosis pilaris – small, rough bumps, present on the face, upper arms, and thighs- Lichenification – thick, leathery skin resulting from constant scratching and rubbing- Papules – small raised bumps that may open when scratched and become crusty and infected- Urticaria – hives (red, raised bumps) that may occur after exposure to an allergen, at the beginning of flares, or after exercise or a hot bath
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may rub their skin against bedding or carpeting to relieve the itch. In children of all ages, the itch can be so intense that they cannot sleep. Scratching can lead to skin infection.

Approximately 5–20% of children worldwide suffer from AD [1]. The incidence of AD seems to be increasing. AD affects all races and geographic locations. However, the incidence seems to be higher in developed countries and mainly in urban areas, especially Western societies [2].

The cause of AD is not known. There is some evidence that genetic factors and probably growing up in a ‘sanitary’ environment (hygiene hypothesis) may predispose to the development of AD [3]. Regarding the genetic predisposition, many patients affected by AD have a family history of atopy, such as asthma, food allergies, AD, or hay fever. Approximately 80% of children with AD may also develop asthma and/or allergic rhinitis later in childhood [4]. An increased rate of sensitization to both food and aeroallergens has been shown to coexist in patients with AD. Sensitization to well-known allergens occurs on average in 50% of children and 35% of adults with AD [5]. At the skin level, food allergies are manifest mainly in two ways: urticaria/anaphylaxis and food-exacerbated AD. Only food-induced AD will be briefly discussed here. In food-exacerbated AD reactions, ingestion of the food, for example cow’s milk protein, can cause an exacerbation of the patient’s symptoms of AD such as erythema and pruritus of the skin lesions. If the reaction is mediated by immunoglobulin E (IgE), symptoms occur almost immediately and up to a few hours after exposure. However,

symptoms may take hours to days to manifest if the reaction is non-IgE mediated. If the culprit food is eaten repeatedly, the subject may present chronic lesions.

Infants with AD may have cow’s milk protein allergy if they also have a history of vomiting, diarrhea, and/or failure to thrive [6]. Approximately 30% and up to 80% of patients with AD may be sensitized to one or more food items. However, the percentage of patients exhibiting symptoms is much lower (15%) [6]. Food-induced AD may be found in 1–3% of children who have mild disease, in 5–10% among those with moderate disease, and in up to 20–33% in those with severe AD [7]. Food-exacerbated AD is rare in adults.

AD coexists in one third of children with recurrent infections, and they present with recurrent rhinitis, cough, and even wheezing following common viral upper respiratory infections. It is important to note that primary immunodeficiencies and allergic disease can coexist [8]. Immunoglobulin A deficiency is a relatively common problem, which is usually asymptomatic and could be associated with celiac disease and atopic disorders. Other immunodeficiencies with associated atopy include common variable immunodeficiency, chronic granulomatous disease, and DiGeorge syndrome.

Quality of Life

In general, quality of life (QoL) is perceived as the quality of an individual’s daily life, that is, an assessment of their well-being or lack thereof. QoL is a broad concept that includes such things as standard of living, community, and family life [9]. Family functioning affects emotional and behavioral functioning of children, which may result in lower ratings on social functioning and well-being QoL domains. Parental and child depression has been linked to lower QoL ratings. Parental stress is also related to lower patient QoL scores. QoL may be affected by personality, education, employment, financial and social situation, as well as medical issues. Health-related QoL (HRQoL) assesses qualities directly related to the disease as well as those that are independent of the disease but may be affected by it. The latter are often neglected by disease severity indexes [10]. HRQoL gives a clearer picture of health than do disease parameters. The greatest difficulty in assessing HRQoL in an infant is that one needs to ask the parents to estimate the loss of quality in the life of their infants, as obviously infants cannot communicate their QoL loss. The literature on QoL has increased substantially over the past decade, whereas before, medical concerns were mainly centered on issues

such as prevention, cure, and costs. Most of the literature focuses on reduction of cases, improvement of symptoms, or money saved by a particular vaccine or treatment. Impact on QoL includes all emotional, social, and physical aspects of an individual's life which, in the case of pediatrics, affect not only the patient but also the family. Although chronic, debilitating illnesses are the ones that will affect patients' QoL the most; even milder illnesses such as AD may affect QoL over time.

***Even milder illnesses such as AD
may affect QoL over time.***

The interest in QoL has not only expanded recently, but it has also deepened concerning the assessment of QoL. The first attempts to measure HRQoL consisted of straightforward evaluations of physical abilities by an external observer, such as whether the patient was able to sit up, walk, take care unassisted of a basic need, or, for some illnesses, they quantitated certain aspects of the impairment, for example, the angle to which an arm or leg could be extended or flexed. In the past decade or so, the current concept of HRQoL has added, for older children and adults, the concept of how their actual situation differs from their own expectations. So, obviously, two individuals with almost exactly the same symptoms of a disease may have very different QoL assessments depending on their past medical and family history as well as family, friends, social support, well-being in other areas not related to their illness, etc. In addition, QoL may vary over time, reacting to changes in external situations. For example, an infant with AD with multiple skin lesions and itching might be handled with patience by the parents. Although afflicted, their life is not what they would have thought it would be, but they still can cope and handle it. Suddenly, the baby's skin manifestations worsen, the skin is itchy, the baby cries all night, and the parents cannot sleep. The father or mother performs poorly at work because of their worries and lack of sleep. Mistakes are made at work, they get reprimanded or even fired, and their whole QoL is profoundly affected by just the worsening of the baby's AD. Alternatively, a child's AD might not worsen much, but a close relative may get ill and, all of a sudden, the problem of AD becomes overwhelming and QoL is affected. As with any situation that involves multiple perspectives, patients', friends', and physicians' ratings of the very same situation may differ significantly. For this reason, the area of QoL has evolved into develop-

ing validated questionnaires directed to the patients and/or their families. In general, such questionnaires are directed towards evaluating multiple aspects of an individual's life such as emotional, social, cognitive, work- or role-related, and even spiritual aspects as well as physical symptoms, treatments, and financial aspects [11].

One important aspect of certain chronic illnesses is the impact that they have on certain life decisions such as social or sport activities that are avoided, places not to go on vacation, jobs not accepted, etc. There are many published surveys assessing the impact of chronic diseases on patients' QoL. However, these studies have not addressed the long-term impact of chronic diseases on critical life decisions taken by patients [12].

Instruments to measure QoL usually assess patients' current experiences and are not designed to assess the long-term impact of disease, which may change over time. Even follow-up studies, which might be expected to encompass more long-term issues, usually compare current impacts before and after a given intervention. In the study by Bhatti et al. [12], adult dermatology patients explained how their chronic disease had influenced major life-changing decisions. The authors evaluated 308 responses (mean age 51.8 years, mean disease duration 19 years). The most frequently reported major life-changing decisions in the dermatology interviews concerned career choice (66%), job (58%), choice of clothing (54%), relationships (52%), education (44%), stopping swimming (34%), moving abroad (32%), not socializing (34%), wearing make-up (22%), and having children (22%). It could be argued that this type of situations concerns more adults with chronic dermatological illnesses than children, but indirectly it may also concern children. For example, parents of an infant with eczema may opt not to go on vacation to the beach because the warm weather may worsen their child's symptoms or a mother may decide not to go back to work after maternity leave in order to take care personally of her child affected by AD. Although the impact of disease on patients' QoL is recognized as important in health care, the impact of illness on those living with the patient has largely been overlooked [13]. There are specialty and disease-specific studies related to the impact of illness on patients' family members in dermatology (see Basra et al. [14], among others). These studies have shown that the impact of illness on families is widespread and severe and that few families are offered appropriate support. In a study exploring family QoL in dermatology, the emotional impact on the family was found to be the most commonly affected area, with 98% of family members interviewed

reporting a degree of emotional distress as a result of the patient's illness [15].

Another aspect that may have long-term consequences on the upbringing of a child is the parental perception of the child's vulnerability. A recent study aimed to assess the prevalence of parental perception of a child's vulnerability in a Dutch community-based sample and its relationship with children's health and HRQoL [16]. In the study, parents of 520 Dutch children aged 5–18 years completed the Child Vulnerability Scale and a sociodemographic questionnaire. In all, 69 (13.3%) children had a chronic illness; 1.9% of children were perceived as being vulnerable, 3.0% in the group aged 5–7 years and 1.7% in the groups aged 8–12 and 13–18 years. Younger age of the child, presence of a chronic illness, and low QoL were associated with parental perception of the child's vulnerability.

Anxiety and depression may also affect parents of a chronically ill child. Van Oers et al. [17] found that mothers of a chronically ill child ($n = 566$) scored significantly higher than the reference group ($p < 0.001$) on anxiety (mean 5.9 vs. 4.8) and depression (mean 4.5 vs. 3.1). Fathers ($n = 123$) had higher depression scores (mean 4.5 vs. 3.6; $p < 0.05$). Interestingly, illness-related characteristics of the child were not related. The authors concluded that parents of a chronically ill child, especially mothers, reported high levels of anxiety and depression.

Although not necessarily pertinent to the topic of AD in infants and young children, another issue that is important in determining QoL in pediatrics is the agreement between parents and their children in assessing the impact of the disease in question. For the impact of infantile asthma on QoL, for example, studies have shown that providers should ask both children and their caregivers about the effects of asthma on the child's QoL, especially with regard to disease effect on activity limitation [18, 19]. These data further contribute to increasing evidence that caregiver reports cannot be used in place of a child's report about disease-specific QoL [20]. Our own study in children with inflammatory bowel disease was aimed to evaluate the degree of concordance between parent and child ratings of HRQoL [21]. The IMPACT-III questionnaire was used to measure QoL in 27 patients (mean age 14.2 ± 3 years) and one of their parents [21]. Results indicated that parent proxy and patient ratings were similar on total IMPACT-III and its related domains (bowel symptoms, systemic symptoms, social functioning, body

image, and treatment/interventions), except that significant differences on emotional functioning ratings were found ($p = 0.003$). In our study, parents served as a good proxy for QoL ratings in this population of pediatric patients with inflammatory bowel disease. The degree of concordance between parent and child scores, however, varied in that parents underreported their child's HRQoL on the emotional functioning domain.

AD and QoL

Patients with skin diseases experience a wide range of symptoms ranging from trivial problems to major handicaps which affect their lives [22–25]. Lewis-Jones [26] stated that 'the misery of living with AD cannot be overstated for it may have a profoundly negative effect on the HRQoL of children and their family unit in many cases'. As AD is one of the most common chronic relapsing childhood dermatoses (UK lifetime prevalence 16–20% by 20 years), with an increasing worldwide prevalence,

Anxiety and depression may affect parents of a chronically ill child.

this has major social and financial implications for individuals, health-care providers, and society as a whole. The good news is that even if symptoms of AD can be uncomfortable and at times difficult to control, the disease in general can be successfully managed and in some cases even prevented [27]. Individuals affected by AD can lead almost normal lives. Having stated this, it needs to be kept in mind that children affected by AD can impact negatively on the entire family's QoL. A child may be fussy and difficult to handle and parents may be unable to keep the child from scratching and rubbing the skin. Although distraction of the child and creating activities that keep hands occupied may be helpful, these require much effort and constant attention from the parents or caregivers. Another issue families face is the social and emotional stress associated with changes in appearance caused by AD. The child may experience difficulties in the nursery, day care, or school which they may be unable to understand. Older children may require additional support and encouragement from family members (table 2).

Quantification of QoL related to disease severity is important in patients with AD, because the assessment provides additional information to the traditional objective clinical scoring systems. McKenna and Doward [28] were surprised that, given the prevalence of pediatric AD and its impact on affected children and their families, so little attention had been devoted to the impact of treatment on

Table 2. Assessment of QoL (adapted from McKenna et al. [29])

1	Impairment (i.e. anxiety, depression, pain, itch, and problems with sleep): loss or abnormality of psychological, physiological, or anatomical structure or function; impairment is related to symptoms
2	Activity: ability of an individual to function (i.e. dressing, walking, personal care, or taking part in sports) as expected; activity includes physical, emotional, social, or other types of functioning
3	HRQoL relates to the effects of a combination of impairment and disability

QoL. Six years have elapsed since that observation and, still, the literature is scarce on this topic. Whenever standardized measures are included in studies, they generally assess outcomes that are of greater interest to physicians than to patients and their caretakers. As stated above, measuring QoL associated with pediatric AD is particularly problematic due to the fact that a high proportion of study participants are too young to provide information about their own QoL. For this reason, McKenna et al. [29] developed the Parents' Index of QoL in Pediatric AD (PIQoL-AD). This is a needs-based measure of QoL that assesses the impact of the child's AD on their main caregiver. Example items from the PIQoL-AD are listed in table 3.

Holm et al. [30] measured HRQoL in patients with AD to analyze discriminant, divergent, and convergent validity by examining the association between various QoL methods and to examine the association between disease severity assessed by an objective Severity Scoring of Atopic Dermatitis (SCORAD) and QoL. HRQoL was assessed at two visits at a 6-monthly interval in 101 patients with AD and 30 controls with one dermatology-specific questionnaire [Dermatology Life Quality Index (DLQI) or Children's DLQI (CDLQI)], one generic instrument (SF-36), and three visual analogue scales of severity and pruritus. Objective SCORAD was used to measure disease severity. Thirty-five children aged 3–14 years were included. Results showed that patients with AD had significantly lower QoL than healthy controls and the general population. DLQI/CDLQI, pruritus, and patient and investigator overall assessment of eczema severity were significantly ($p < 0.0001$) and positively correlated with SCORAD, while the generic questionnaire showed only poor correlation. The authors concluded that AD has an impact on HRQoL. Patients' mental health, social func-

Table 3. Integrated issues related to PIQoL-AD

– I have to be careful what she/he wears
– I never get a good night's sleep
– I feel I have little freedom
– All my attention has to go to her/him
– I worry about the way she/he looks
– It is difficult to find time for shopping
– There is a lot of tension in the family
– She/he is very moody
– She/he cannot be comforted
– She/he is very demanding
– She/he misses out on a lot of childhood activities
– Other children don't like holding her/his hand

tioning, and emotional role functioning seem to be more affected than physical functioning. Patients scored their disease as more severe compared with the investigator assessment. High correlations were found between patient and investigator assessments of severity, although patients scored their disease as more severe compared with the investigator. This difference was significant.

The impact of AD on the mother's health was studied in Singapore [31]. The study examined maternal perceptions of pediatric AD and its impact on the family and determined risk factors including severity of AD, maternal physical and mental health, QoL of patients, and sociodemographics which predict a negative family impact. One hundred and four patients with AD and their mothers were studied. Their mean age (\pm SD) was 6.4 ± 4.3 and 37.2 ± 6.6 years, respectively. In multiple regression analysis, SCORAD appeared to be associated with a negative family impact and the association remained significant after adjustment for bio-psycho-social factors and HRQoL of patients. The association turned out to be insignificant after adjustment for physical and mental health of the mothers. The authors concluded that their results show that the severity of pediatric AD leads to a negative family impact through reduction of physical and mental health of the mothers and is independent of patients' HRQoL and sociodemographics. They recommended that the current approach for managing pediatric AD in Asian society should include early multidisciplinary intervention, aiming at enhancing physical and mental health of mothers, while minimizing the negative impact on the family and social isolation.

A study from Japan also looked at the impact of AD on QoL [32]. The authors used the Japanese version of Skin-dex-16 in a cross-sectional and longitudinal questionnaire study on 162 adult patients. Three to six months

after the initial testing and treatment, 135 (83.3%) of the patients again completed Skindex-16 and also answered a general question about whether their skin condition had improved, had remained the same, or had become worse. The scores of Skindex-16 of 162 patients with AD were significantly higher than those of patients with isolated lesions, particularly in the symptoms and emotions scales. Patients with severe AD showed significantly higher scores on the three scales (symptoms, emotions, and functioning), and there was a significant positive correlation between the severity and the three scale scores. Among the patients whose dermatitis had improved, the scores of Skindex-16 significantly decreased. On the other hand, patients who reported that their dermatitis had become worse showed an increase in the scores.

It is obvious that the impact of AD on QoL affects people of all ages. Another study that included 239 AD patients aged 4–70 years showed that patients with AD had inferior scores on vitality, social functioning, and mental health subscales compared with individuals in the general population [33]. Patients with AD had inferior mental health scores compared with those with diabetes or hypertension and inferior social functioning scores compared with patients with hypertension. When compared with a psoriasis cohort, patients with AD had inferior

scores in the physical role, vitality, social functioning, emotional role, and mental health domains.

Finally, an international study performed in the Czech Republic, Singapore, Brazil, the Netherlands, and South Korea on QoL and family QoL in children with AD found a similar impact of the disease as rated by parents of 419 children under the age of 4 years in all countries [34].

Patients with AD had inferior mental health scores compared with those with diabetes or hypertension and inferior social functioning scores compared with patients with hypertension.

Conclusion

Results from multiple studies demonstrate that AD has an impact on HRQoL, particularly on social functioning and psychological well-being. Patient-assessed severity of AD correlates with HRQoL decrements, indicating a greater HRQoL impact with greater disease severity. AD has as large an impact on HRQoL as several chronic conditions and other dermatologic conditions.

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