

Why and how should we consider the Quality of Life of children with atopic dermatitis and their family?

ATOPY

BASIC

AD is often described as a skin disease, but it can be extremely disabling and cause psychological problems for affected children and their families. Quality of Life (QoL) assessment in AD patients has shown that the disease is one of the most poorly rated.¹

Atopic dermatitis: a proven adverse impact on children's quality of life

With its effects on the skin, sleep, everyday activities (school, sport, etc.) and emotional impact, AD, like other skin diseases, can cause severe disability and handicap in children. The major impact of widespread inflammatory skin disease, particularly atopic eczema, on children's quality of life was confirmed in a 1995 study.²



And families are also affected

Parents and other family members of children with AD are often involved in caregiving. That can have significant effects on family dynamics as well as family life in general. Research has revealed that families of children with AD often report lower quality of life than families of healthy children. Unsurprisingly, the family impact of the disease has been positively correlated with AD severity, with more severe cases associated with increased family disruption.¹

Lower QoL may affect compliance



The effects of AD on the family can be extensive and pervasive. Unfortunately, because AD is not life-threatening, families seldom receive potentially useful educational or psychosocial support, which can result in further stress and frustration.¹

A perceived lack of support from medical professionals can lead to decreased trust in the medical system, which in turn may result in decreased adherence to treatment and suboptimal medical, psychosocial and economic outcomes.¹

QoL: Beyond pharmaceutical treatment, the necessary involvement of health professionals

Specialist care for AD patients may also be useful in decreasing the family impact of the condition. A recent study determined that an episode of specialist care was associated with reduced family impact. It also found that visits to specialists led to fewer out-of-pocket nonmedical care expenses.¹

Furthermore, simple acknowledgment of potential effects on the family by healthcare workers can improve the physician-patient relationship and so trust in the profession. With improved physician-patient (parent) relationships, adherence to treatment protocols can also be improved. Increased adherence will in turn improve treatment outcomes, which has implications for the patient and societal costs associated with the disease.¹

Improving QoL: emollients may also help

The application of moisturizers should be an integral part of the treatment of AD patients as there is strong evidence that their use can reduce disease severity and the need for pharmacologic intervention.³

They increase the skin's hydration, lessen symptoms and signs including pruritus, erythema, fissuring and lichenification, and give some reduction in inflammation and AD severity.³

It has been demonstrated that this effect on symptoms has a significant impact on improving parents' QoL with better health, quality of sleep, etc.⁴

GOING FURTHER

Impact of AD on the family, as described by parents⁵

Practical care issues	General burden of extra care, e.g. relating to household cleaning and washing, preparing meals and shopping
Psychological pressures on parents	Psychological pressures including feelings of guilt, exhaustion, frustration, resentment and helplessness
Family lifestyle	Feeling of not having a "normal" family life (i.e. family pets not allowed, family diet affected, restricted use of household products such as washing powders and bath products)
Sleep disturbance	Night-time itching and scratching causing delays in settling the child to sleep and night-time waking, requiring parental help and causing frustration and exhaustion
School	Problems with school life, teasing and bullying leading to parental anxiety, poor school attendance, etc., causing problems for working parents
Effects on child behaviour	Behavioural disturbances such as being naughty, irritable, bad-tempered, easily bored and hurtful to other family members during AD flare-ups
Social life	Reduced ability to get out to entertainment and pursue hobbies because of tiredness. Sporting activities, especially swimming, often restricted. In addition, difficulties in finding suitable babysitters
Relationships	Interpersonal relationships adversely affected by caring for a child with AD. Tiredness from sleep loss causing friction. Some parents describe themselves as overprotective: this can lead to feelings of jealousy in the carer's partner and in siblings. AD may even be a factor in marriage breakdown
Practical support	Receiving inadequate support from teaching and medical professionals. The lack of support and difficulty in obtaining specialist referral can prompt a change of practitioner
Holidays	Restricted choice of holidays because of sleeping problems, the climate and special requirements for creams, foods, clothing and bedding
Financial aspects	Special diets, extra laundry, bathing and clothes add to the cost of having AD

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