

EFFECTS OF CHILDHOOD ATOPIC ECZEMA ON THE QUALITY OF LIFE

E Bronkhorst¹ | BPharm, MSc(Med)

N Schellack¹ | BCur, BPharm, PhD

MH Motswaledi² | MBChB, MMed(Derm), FCDerm (SA)

1. Department of Pharmacy, Sefako Makgatho Health Sciences University

2. Department of Dermatology, Sefako Makgatho Health Sciences University

Email | natalie.schellack@smu.ac.za

SUMMARY

Atopic eczema is one of the most common chronic inflammatory skin diseases affecting children. Disease presentation may influence how the child perceives him- or herself and may have an influence on the psychological development of the child or influence the quality of life. The impact of health-related quality of life in children suffering from atopic eczema can be measured by using assessment tools such as the Children's Dermatology Life Quality Index (CDLQ) and the Infant Dermatitis Quality of Life Index (IDQOL), together with the Dermatitis Family Impact (DFI) tool to assess the impact on family members or caregivers. Psychological factors identified by using these assessment tools include impaired emotional development, increased behavioural problems and sleep difficulties. It may interfere with intellectual and social development of children. Parents may experience frustration and anger which may result in lower social functioning, financial strain and reduced overall wellbeing. The quality-of-life assessments and psychological interventions should form part of the treatment process for atopic eczema.

This article has been peer reviewed.

INTRODUCTION

Atopic eczema (AE), or atopic dermatitis, is one of the most common chronic inflammatory skin diseases in children,¹ affecting approximately 17% of children in the United States and between 5–20% of children in Western communities.^{1,2} A systematic review performed in 2012 has found the prevalence of AD in South-Africa to be around 17% and in Kenya up to 20%, with trends in AD increasing.³ The condition most often begins in infancy or early childhood, with more than 90% of cases appearing in the first five years of life. One-third of these children can also be affected in adolescence.² Atopic eczema is related to genetic factors, changes in the immune system of the patient or environmental influences.⁴ This period of life is critical to the psycho-social development of a child.⁵

Disease presentation may influence how the child perceives him- or herself as the disease is characterised by inflammation caused by pruritus. This condition may occur after exposure to an allergen, or after exercise or a hot bath and may develop into papules which may open when scratched, becoming infected, weeping and crusty. Constant rubbing or scratching may result in thick leathery skin, with accentuated skin markings called 'lichenification'. Some patients may present with xerosis or dry skin with scales, hyperpigmented eyelids, cheilitis or inflammation of the skin of the lips and an atopic pleat or extra fold of

skin that occurs under the eye.¹

Stress has an impact on the progression of the disease as there is interplay between the skin disease and stress. This may form a core part of counselling for both patients and parents.⁶ Stress has an impact on the intensity of the itch and an association has been found between the severity of atopic eczema and stress.⁷ Environmental and lifestyle factors are important in the expression of eczema flares. Daycare attendance increases the stress levels of young children, especially in the first two years of life, and may lead to increased prevalence of eczema flares.⁸ Furthermore, attendance at daycare facilities may either awaken or prolong atopic eczema flares. It may be difficult to provide the increased attention requirements to children who suffer from atopic eczema attending daycare due to the large groups of different children. In addition, teachers who are not knowledgeable about the disease may not be aware of special requirements for example nutrition, irritant, climatic or allergen triggers.⁴

THE INFLUENCE OF ATOPIC ECZEMA ON THE QUALITY OF LIFE

Quality of life can be defined as the quality of an individual's daily life, or an assessment of their wellbeing or a lack thereof, and include aspects such as standard of living and life in the family and community.¹ According to the

World Health Organisation (WHO), quality of life includes the individual's perception of their position in life and can be influenced by physical health, psychological state and social relationships. Disease severity indexes often neglect the influence of the disease on quality of life.¹

Quality of life is also affected by personality, education, employment, financial and social situation as well as medical issues. Health-related quality of life assesses qualities directly related to the disease, as well as those that are independent of the disease but may be affected by it.¹ Impact on quality of life includes all emotional, social and physical aspects of an individual's life, which – in the case of paediatrics – not only affects the patient but also the parents and the rest of the family.¹

Inferior health-related quality of life and increased psychological distress was reported among the patients affected by atopic eczema.² In a similar manner, the quality of life of parents, caregivers or family members is also reduced due to the nature of the disease. Depending on the disease severity, the caregiver may spend up to two to three hours a day caring for a patient with atopic eczema.²

Using five different quality-of-life assessment tools Maksimovic et al⁹ concluded that with increased disease severity, greater impairment of quality of life was found in both social

functioning and mental health scores when compared to the general population. Quality-of-life impairments were evident in both children suffering from the disease as well as parents.⁹ This is illustrated in Figure 1 where each aspect of life affected by atopic eczema is depicted.

ASSESSMENT TOOLS FOR QUALITY OF LIFE

The first attempts to measure health-related quality of life consisted of straightforward evaluations of physical abilities by an external observer such as a healthcare worker. Certain aspects of physical impairment such as sitting up or walking were quantified. In the past decade, the current concept of how a child's or their parents' actual situation differs from their own expectations has been added to the tools. Although the impact of disease on patients' quality of life has been recognised as important in healthcare, the impact of illness on those living with the patients has largely been overlooked.¹ Studies have shown that few families of patients suffering chronic illness are offered appropriate support.²

The Children's Dermatology Life Quality Index (CDLQ) and the Infant Dermatitis Quality of Life Index (IDQOL), together with the Dermatitis Family Impact (DFI), are quality-of-life measures that have been employed in several studies, is a user-friendly cartoon aimed at educating the child.^{2,5,8} The use of health-related quality-of-life questionnaires

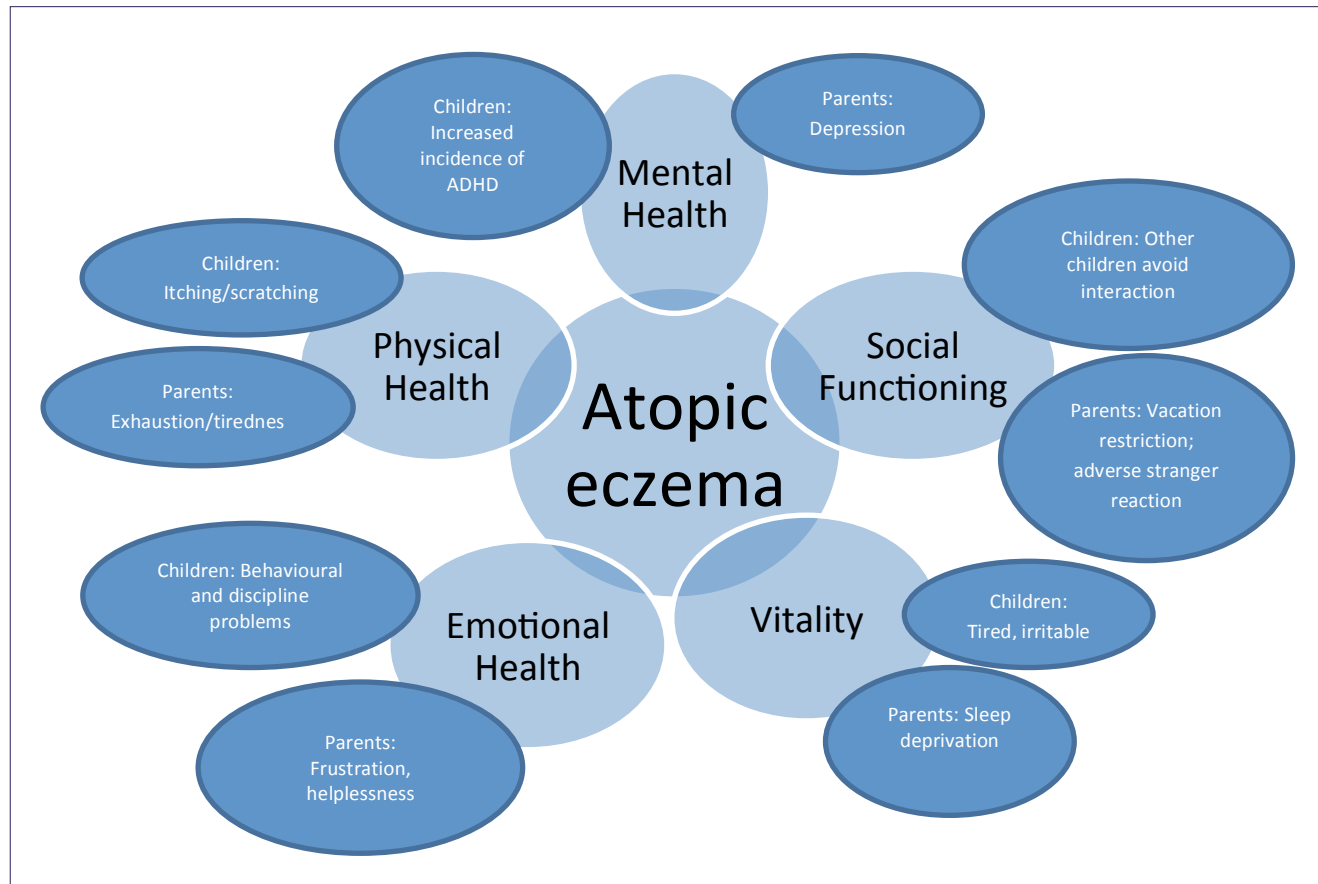


Figure 1: The influence of atopic dermatitis on quality of life aspects (Adapted from Lifschitz, 2015)

is recommended to be used by clinicians as an outcome measure for assessing the impact of atopic eczema. Their use, in conjunction with clinical measures, has been recommended by the National Institute for Health and Clinical Excellence.¹⁰

McKenna et al¹¹ developed the Parents' Index of Quality of Life (QoL) in paediatric patients suffering from atopic eczema which is a needs-based measure of QoL that assesses the impact of the child's atopic eczema on their main caregiver. Measures included in this assessment tool address issues surrounding what a child should wear, not getting a good night's sleep, having limited freedom, worries about the appearance of the child and aspects causing tension in the family unit, such as difficulty in comforting the child and difficulty of interacting with peers.¹¹

Results from these scoring systems showed that children with atopic eczema and their families had significantly lower quality of life than healthy controls and the general population. This has shown that atopic eczema has an impact on health-related quality of life. In patients suffering from atopic eczema, mental health, social functioning and emotional functioning appear to be more affected than their physical functioning.¹⁰

EMOTIONAL AND SOCIAL FUNCTIONING

Atopic eczema patients have been known to suffer from different psychosocial problems, which include frustration with disease, and embarrassment and anger about their appearance.² The severity of the skin disease may influence the association with mental health disorders.¹²

PROBLEMS EXPERIENCED BY INFANTS

When atopic eczema affects infants, skin sensation is often altered. This can result in impaired emotional development, because the skin is critical in sensory perception and communication. Skin contact between infants and parents contributes to the feelings of wellbeing and self-esteem.⁶

PROBLEMS EXPERIENCED BY CHILDREN AND ADOLESCENTS

Children suffering from atopic eczema display increased behavioural problems, such as increased dependency, fearfulness and sleep difficulties. These behavioural problems can affect social development and may even interfere with a child's intellectual development. Social relationships may be affected, as peers may be afraid of catching infection and the physical appearance may lead to exclusion of social interaction and sports participation.² Social and emotional stress associated with changes in appearance caused by atopic eczema, may cause additional stress to the child as well as the family.¹

Sleep patterns are affected in the majority of children with atopic eczema (up to 84%). Itching and scratching causes them to wake frequently during the night. Sleep

deprivation results in increased drowsiness during the day and may influence their intellectual development. Sleep deprivation is also one of the most important factors causing poor family relationships.² Sleep abnormalities are very prevalent in children with atopic eczema and may influence the development of sleep patterns in young infants and children, causing chronic, behaviour-based sleep problems.⁵

Although atopic eczema has its peak in infancy, certain aspects of the condition, such as dry skin and the itchy rash, may continue into adolescence and adulthood. In adolescence the eczema may reappear, often along with other co-morbid conditions such as seasonal respiratory allergies (hay fever) and asthma. This provides an additional challenge to the adolescent as he or she also has to focus on social interaction, studies, sports and other extracurricular activities. The changes experienced in his or her skin such as dry and/or inflamed skin may cause isolation and separation from friends. This, together with the other challenges listed, often reduces the quality of his or her life.^{13,14}

PROBLEMS EXPERIENCED BY PARENTS

Distracting the child to prevent scratching and rubbing the skin may require much effort and constant attention from the parents or caregivers, which may put strain on the relationship.¹ Sleep deprivation of the children may have a resultant negative effect on the parents' work performance and coping skills.²

Parents of infants and children with atopic eczema are often anxious, frustrated and angry and this may be directed at both their children and their physicians. Parents will often feel that physicians will prescribe desperate remedies, numerous referrals and unnecessary testing.⁶ How the family functions as a unit influences the emotional and behavioural wellbeing of the children, resulting in lower ratings on social functioning and wellbeing. Parental and child depression as well as parental stress have been linked to lower quality-of-life ratings.

Parents of children with flares of atopic eczema have many worries related to medication use, including the fear of using topical corticosteroids.⁵ Topical corticosteroid phobia is the fear of using topical corticosteroids, because of dangers such as thinning the skin and even tolerance. This fear is reported in up to 73% of parents of atopic eczema patients and may lead to non-compliance and treatment failure.¹⁵

Parents also experience financial problems due to the atopic eczema of their children. Studies have concluded that the financial impact of treating atopic eczema was similar to other chronic diseases such as epilepsy, emphysema and psoriasis.² This places an added financial burden on the family with additional expenditure on emollients, topical steroids, clothing and bedding, laundry and possible consultation with alternative medicine practitioners.⁶

TABLE I: CHECKLIST FOR SKINCARE ROUTINE

SKINCARE FOR ATOPIC ECZEMA	CHECKLIST ✓
MORNING	
Have you applied your topical corticosteroid to the affected rash areas?	
Have you applied appropriate moisturiser to your eczema prone areas? – If going into sunlight this may be substituted with an emollient based sunscreen.	
EVENING	
Have you showered in lukewarm water using an unscented liquid cleanser?	
If you are male and old enough to shave, you can use the same type of cleanser as stated before or alternatively an unscented shaving cream.	
Have you patted yourself dry after you have showered?	
Have you applied your topical corticosteroid to the affected areas?	
Have you taken your medicines before bedtime as prescribed by your doctor?	

SOME INTERVENTIONS TO ENHANCE QUALITY OF LIFE

Patients diagnosed with atopic eczema and their parents can be referred to trained healthcare providers to assist with psychological and educational interventions, in order to enhance their quality of life.

PSYCHOLOGICAL INTERVENTIONS

The main types of psychological intervention include psychological techniques using arousal-reduction techniques. This is very similar to relaxation techniques and includes progressive relaxation, a technique that teaches patients to tense different muscles and then to release that tension. Autogenic training involves increased awareness of the body, guided imagery or visualisation. This teaches patients to use imagery associated with calmness to induce the related feeling in their own body. Biofeedback creates awareness about physiological responses, usually with the use of instrumentation and hypnotherapy involving the creation of a suggestible state for an individual.¹⁶

Behavioural interventions involve the application of behavioural theory to modify behaviour, such as habit reversal to modify unhelpful scratching and even caregiver training programmes, where caregivers are trained to use charts to record and reward progress.¹⁶

Psychological therapies focused on internal processes such as cognitive behavioural therapy, counselling and family therapy can be implemented to assist the individual in understanding the links between their own thoughts and thinking processes and behaviour, as well as encouraging family members to focus on relationships within the family unit.¹⁶

EDUCATIONAL INTERVENTIONS

Educational interventions are designed to teach management strategies related to prevention, management and the use of social skills targeted at children or their caregivers. This can be done through problem-solving, role-play, computer-assisted instruction, short video clips or booklets. Through any of these methods information about the disease, treatment instructions and management

and prevention strategies can be given to children, parents or their caregivers, and may lead to improved disease control and quality of life.¹⁶

Successful management involves educating patients and their families about atopic eczema, reducing signs and symptoms and preventing the degree and frequency of flairs. By accomplishing an improvement in the frequency of symptoms, emotional and psychological stress to the patient and the family can be reduced and the quality of their lives improved.¹⁷

Educational strategies may include providing the child and/or their parents with a checklist that they can use to guide their therapy. Table I is an example of a checklist that can be given to parents or older children and adolescents in order to create an awareness of their condition.¹³

CONCLUSION

Challenges experienced by children suffering from atopic eczema include sleep deprivation, scratching and itching, difficulty of interacting with peers and behavioural and discipline problems. Measurement of the impact of skin disease on quality of life and emotional wellbeing is important for our understanding and management of skin conditions as psychosocial factors play an important role in the itch-scratch cycle. Quality-of-life measures such as the emotional impact of atopic eczema on both children and their parents are often underestimated. The greater the disease severity, the more quality-of-life measures will deteriorate. This can be addressed using more conscious psychosocial and educational interventions as part of treatment, as this can improve treatment outcomes and the quality of life.

DECLARATION OF CONFLICT OF INTEREST

The authors declare no conflict of interest.

REFERENCES

1. Lifschitz C. The impact of atopic eczema on quality of life. *Ann Nutr Metab* 2015;66:34–40.
2. Basra M, Shahrukh M. Burden of skin diseases. *Expert Rev Pharmacoecon Outcomes Res* 2009;9:271–283.

3. Zhao CY, Wijayanti A, Doria MC, Harris AG, et al. The reliability and validity of outcome measures for atopic dermatitis in patients with pigmented skin: A grey area. *International Journal of Women's Dermatology* 2015;1:150–154.
4. Peter FH. Day care (quality) and differences in children's health and personality characteristics. Available from: http://www.diw.de/documents/vortragsdokumente/220/diw_01.c.425206.de/v_2013_peter_day_eea.pdf (accessed 27 November 2015).
5. Chamlin SL, Frieden IJ, Williams ML, Chren MM. Effects of atopic eczema on young American children and their families. *Pediatrics* 2004;114:607–611.
6. Barankin B, DeKoven J. Psychosocial effect of common skin diseases. *Can Fam Physician*. 2002;48:712–716.
7. Schut C, Weik U, Tews N, Gieler U, et al. Coping as mediator of the relationship between stress and itch in patients with atopic eczema: a regression and mediation analysis. *Exp Dermatol* 2015;24:148–150.
8. Cramer C, Link E, Bauer CP, Hoffman U, et al. Association between attendance of day care centres and increased prevalence of eczema in the German birth cohort study LISAplus. *Allergy* 2011;66:68–75.
9. Maksimović N, Janković J, Marinković J, Sekulović LK, et al. Health-related quality of life in patients with atopic eczema. *J Dermatol* 2012;39:42–47.
10. Beattie PE, Lewis-Jones MS. An audit of the impact of a consultation with a paediatric dermatology team on quality of life in infants with atopic eczema and their families: further validation of the Infants' Dermatitis Quality of Life Index and Dermatitis Family Impact Score. *Br J Dermatol* 2006;155:1249–1255.
11. McKenna SP, Whalley D, Dewar AL, Erdman RA, et al. International development of the Parents' Index of Quality of Life in Atopic eczema (PIQoL-AD). *Qual Life Res* 2005;14:231–241.
12. Yaghmaie P, Koudelka CW, Simpson EL. Mental health comorbidity in patients with atopic eczema. *J Allergy Clin Immunol* 2013;131:428–433.
13. Howard M. Challenges of Managing Eczema in Teenagers. *Medical Experts*. 2014. Available from <http://www.childrenshospitaloakland.org/Uploads/Public/Documents/PDF/challenges-of-managing-eczema-in-teenagers-%20childrens-hospital-oakland.pdf> (accessed 27 November 2015).
14. Levy M. Pediatric Dermatology. An Issue of *Dermatologic Clinics*. Clin Dermatol 2013;31(2); ISSN 07338635
15. Smith SD, Stephens AM, Werren JC, Fischer GO. Treatment failure in atopic eczema as a result of parental health belief. *Med J Aust* 2013;199:467–469.
16. Ersser S, Cowdell F, Latter S, et al. Psychological and educational interventions for atopic eczema in children. *The Cochrane Library*. 2014. Published online: 2014, Jan 7.1:CD004054.doi:10.1002/14651858.CD004054.pub3 (accessed 27 November 2015).
17. Krakowski A, Eichenfield L, Dohil M. Management of atopic eczema in the pediatric population. *Pediatrics*. 2008;122:812–824.

Welcome Letter

ALLSA CONGRESS 2016

Cape Town

We are all very excited to welcome you to the Mother City for the 25th Annual ALLSA Congress. This event will take place at the new Century City Conference venue, which promises to provide a spacious and stimulating environment for our delegates and exhibitors.

Our theme is Allergy...or not? This year's congress focuses on allergy and allergy mimickers, coupled with an overview of the latest trends in allergy and clinical immunology.

There will be 4 workshops, as these proved to be extremely popular in 2015. This year we cover Occupational Allergies, Respiratory Problems, a Skin workshop and a Food workshop. They are designed to appeal to generalists and specialists, as well as nurses, pharmacists and dietetic colleagues.

Our 3 plenary sessions will cover some cutting edge topics, including the latest in adverse drug reactions, the concept

of the microbiome as well as gastroenterology topics such as eosinophilic disease, coeliac and other bowel disorders. We are pleased to announce that we have 2 international speakers, both experts in their fields.

Professor CJ Mulder, an adult gastroenterologist is an expert in inflammatory and eosinophilic bowel conditions. Dr Mark Furman is a paediatric gastroenterologist and contributed to the latest UK/BSPGHAN coeliac disease guidelines. He will give us an update on how to differentiate between inflammatory bowel diseases and allergies.

We extend a sincere welcome to our exhibitors. Without their loyal support over the years, we would not be hosting this exciting event. Please visit the trade stands, and pay special attention, so that you may vote for the best exhibitor. There will be a special trophy handed out at the gala dinner.

See you all in Cape Town.



Di Hawarden
Committee Member



Sarah Karabus
Committee Member



Shaunagh Emanuel
Committee Member