Review Article

THE IMPACT OF ATOPIC DERMATITIS ON THE PSYCHO-SOCIAL WELLBEING OF CHILDREN AND THEIR FAMILIES

Annemarie Gouws | Dip Allerg (SA)
Medical Officer, Emergency Department, Hermanus Medi-Clinic
Email | agouws.allergy@gmail.com

SUMMARY
Social and emotional wellbeing is a prerequisite of optimal development, healthy inter- and intrapersonal relationships, academic attainment and establishing socially acceptable behaviour-patterns. Atopic Dermatitis (AD) is a complex disease that can adversely affect all of the above domains and have long-term consequences if not managed adequately. A high percentage of AD patients present with this disease in the first five years of life, which is a critical period in their physical and psycho-social development.

This article explores the systems involved in social and emotional functioning as well as the impact of AD on these systems. Sleep-deprivation, the discomfort caused by the disease and its treatment, disfigurement, stigmatisation, isolation, parenting styles and low resilience levels are considered as possible factors in promoting poor psycho-social outcomes.

Strategies will be discussed to improve psycho-social wellbeing in the paediatric population suffering from Atopic Dermatitis. These include improving practitioner awareness, early diagnosis, appropriate referral, a multi-disciplinary approach, use of support groups, positive parenting strategies and promoting the development of resilience.

Emotional and psycho-social wellbeing decreases stress levels and stress-related disease exacerbations, improves adherence to treatment, social interactions and behavioural problems, and increases the ability to adapt to the disease and its treatment.

INTRODUCTION
The World Health Organisation (WHO) defines health as ‘a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity’. It is therefore important to consider our patients holistically rather than only focusing on the physical aspects of a disease such as AD.

The terms ‘wellbeing’ and ‘quality of life’ (QOL) are often used interchangeably, and incorporate both objective and subjective aspects of a person’s life experience. Psycho-social wellbeing (PSW) is the foundation for optimal development, the establishment of healthy behaviour patterns, and educational attainment in children. It is associated with accomplishing personal competencies such as emotional resilience, positive self-esteem and interpersonal skills, which enables children to take advantage of opportunities and deal with adversities in life. This article elaborates on the dimensions of PSW in childhood (ages 0–12 years) and investigates the influence of AD on these dimensions. Strategies are discussed that promote positive outcomes in the domains of the psycho-social welfare of our patients.

PSYCHO-SOCIAL WELLBEING IN CHILDHOOD
PSW refers to the way a person thinks, feels and interacts with themselves and others. It varies over time and according to developmental level. PSW includes perceptions of current and future physical, emotional and social welfare; it is influenced by the physical and social environment (including family relations and social connectedness). The dimensions of PSW are influenced by the current status of physical health.

Various models have been developed to conceptualise this complex phenomenon. I refer to Bronfenbrenner’s Ecological Model as well as Hamilton and Redman’s Model in an attempt to simplify the different aspects of PSW. Two interdependent dimensions are described:

• Individual dimension:
The expression of these characteristics is dependent on factors such as developmental stage, age, temperament, genetics and physical health. It is developed in a centrifugal manner. The presence of disease or disability will have a negative impact on PSW. 5

THE IMPACT OF ATOPIC DERMATITIS ON THE PSW OF CHILDREN

The terms AD or Atopic Eczema (AE) are used interchangeably to refer to a chronic, inflammatory, pruritic skin condition that often commences in early childhood and varies in severity and duration. 6

AD is a common condition in childhood with an estimated prevalence of 15-30% according to data collected by Phase 3 of the International Study of Asthma and Allergies in Childhood. The onset of AD in infants less than 6 months of age is quoted as 45%, as 60% during the first year of life and as 85% before the age of 5 years. 7 This period corresponds to the most critical time for physical and psycho-social development. 8 It is therefore not surprising that AD can have such a profound influence on the PSW of afflicted children, even those presenting with milder forms of the disease. 8,9

IMPACT OF AD ON INDIVIDUAL/INTERNAL DIMENSIONS OF PSW

INTRAPERSONAL CHARACTERISTICS:
Children suffering from AD often have negative self-esteem (subjective perception of self-worth) and poor self-image (subjective perception of abilities, appearance). They experience frustration, fussiness, irritability, unhappiness, loneliness, self-consciousness and emotional sensitivity. Parents reported that their AD children often cried, and were nervous and insecure. Researchers observed perfectionism, rigid and obsessive thought patterns, anxiety, depression, obsessive and compulsive traits in paediatric AD patients. 5 Low resilience seems to be a common trait among children with AD. Resilience refers to the capacity to recover from (or adapt after) an insult in order to maintain functional capacity. This characteristic enables certain individuals to ‘bounce back’ and recover from adverse circumstances. Higher resilience levels are associated with higher self-esteem and good interpersonal relationships. 10 We shall discuss ways of fostering resilience shortly.

INTERPERSONAL/RELATIONAL CHARACTERISTICS:
Afflicted children present with difficulties in social interaction and impaired social competence. 10 Caregivers report a higher level of dependency, clinginess, fearfulness and isolation in comparison to their healthy peers. 8

Problematic behavioural patterns that include hyperactivity, impaired attention, scratching to get attention; stubbornness, aggressiveness, disruptive and oppositional behaviour have been documented, especially in young
children with AD. A significant association was found between Attention Deficit Hyperactivity Disorder (ADHD) and AD. It is suggested that these behavioural difficulties are possibly mediated by disturbed sleeping patterns, difficulty in coping with the discomfort of AD and its treatment, disfigurement, stigmatisation and disciplinary challenges.

**IMPACT OF AD ON ENVIRONMENTAL DIMENSIONS**

**FAMILY ENVIRONMENT:**
AD profoundly affects the personal, emotional, social and financial wellbeing of families with children suffering from AD. Activities such as treatment administration, complex skincare routines, domestic chores related to allergen avoidance measures, purchase and preparation of additive- and allergen-free meals for the AD child are energy and time consuming (estimated time expenditure up to 3 hours/day). This burden can have a negative impact on spousal relationships, interfere with giving adequate attention to siblings and leave little opportunity for the primary caregiver to enjoy leisure activities.

A lack of social support (unsolicited advice, accusations of neglect or abuse), isolation, helplessness, guilt, frustration and fatigue impair the emotional wellbeing of the caregiver, leading to anxiety and depression. Sleep disturbance is reported to be the most stressful aspect of caring for the AD patient and affects parents as well as siblings. Incessant itching and scratching the most difficult to control. Disciplinary challenges are encountered due to disturbed family dynamics (parental conflict, discord, maternal fatigue, depression, overprotection), lack of consistent disciplinary structure (e.g. caregivers capitulating as a result of feeling sorry for the child, avoidance of conflict in an effort to avoid distress induced disease exacerbations), and child specific factors (chronic illness, ADD or ADHD, difficult temperament).

The financial burden is substantial and can include a loss of income due to impaired productivity as a result of sleep deprivation, time taken off work (care of unwell child, doctor’s visits), expensive treatments and transport cost.

**SCHOOL/COMMUNITY ENVIRONMENT:**
AD patients participate significantly less in sports, leisure and group activities (structured or unstructured) than members of their peer group. This is partially due to fatigue, disease factors (flares, severe/persistent or widespread AD), the embarrassment associated with visible lesions (particularly facial AD) and stigmatisation. Patients with moderate to severe AD avoid staying over with friends or extended family members through a fear of disease exacerbations (allergen exposure and disruption of treatment regimen).

Parents and AD patients express concerns regarding teasing, bullying, nasty nicknames and insensitive comments by peers and strangers. AD sufferers experience social distancing and rejection due to the public misconception that they are ‘dirty and contagious’. This makes participating in activities and establishing or maintaining relationships with other children more challenging and may even lead to school avoidance. Despite the difficulties that these children face in interpersonal relationships, they have a desire to participate, belong to a group and be valued as individuals.

**THE ROLE OF SLEEP DEPRIVATION IN PSW**
Sleep dysfunction (including delayed onset, multiple awakenings and overall reduced sleep efficiency) occurs during flares but persists during remissions. Co-morbid asthma and allergic rhinitis may exacerbate sleep dysfunction. Sleep deprivation is associated with daytime
It is hypothesised that pruritus-induced sleep disruption becomes a persistent behaviour-based acquired sleep pattern which may be perpetuated by the habit of co-sleeping with parents. This strategy is adopted in an attempt to prevent awakenings and scratching. Unfortunately, parental sleep deprivation and exhaustion are aggravated by this practice, which correlates with maternal anxiety, depression and poor QOL in both parents and AD patients.

STRATEGIES TO IMPROVE PSW OF PAEDIATRIC ATOPIC DERMATITIS PATIENTS

I. PROMOTE PRACTITIONER AWARENESS
Healthcare professionals should be cognisant of the extent of PSW impairment that may result from AD in sufferers as well as their families. The impairment of QOL is considered to be equal to that of patients with Insulin Dependent Diabetes Mellitus. An attempt should be made to explore PSW impairment in a practical and effective manner following a family-centred approach (encourage input and participation in decision-making from parents and children). Good-quality, relevant information should be offered, tailored to the needs of the family, in order to promote an understanding of the condition and empowering family members to manage AD effectively. This approach promotes satisfaction with medical care, increases patient compliance, enhances sense of control over the disease and improves treatment outcomes.

II. MULTI-DISCIPLINARY TEAM APPROACH
AD is a multi-faceted disease and is best managed by a multi-disciplinary team approach. Specialty care from dermatologists, paediatricians, allergist-immunologists and dermatology nurses decreases the burden of disease. Appropriate referral to psychological and psychiatric services may be appropriate and therapeutic options such as relaxation training, habit reversal training, cognitive–behavioural techniques and stress management training may serve as an adjunct to conventional therapy.

Nurse educators play a critical role in providing AD-specific structured education, practical demonstrations of skin-care regimens and family support. Repeated sessions are often required to establish positive disease management skills. This approach has been shown to dramatically improve disease severity in children with poorly controlled AD.

III. SUPPORT GROUPS
Formal or informal support groups organised by either professional facilitators or lay persons (e.g. parents of children suffering from AD) can be extremely helpful. They provide access to educational resources, practical advice, emotional comfort, moral support, non-judgemental social interaction and networking to find practitioners with an interest in AD management in various geographical locations.

Participating in support groups may help families to develop positive coping strategies, increase compliance with treatment and reduce psycho-social morbidity. The South African National Eczema Association (SANEA) is such a support group. It provides information on AD and its treatment, a support service and networking opportunities. The association’s telephone number is +27 (0)78 320 4054; it is also accessible through social media.

IV. POSITIVE PARENTING
Parenting a child suffering from a chronic illness is challenging and stressful for parents. However, the basic principles of good parenting are still applicable: establishing a daily family routine (e.g. eating dinner together at the same time), maintaining discipline and providing encouragement without being overly protective or permissive. The parent needs to become skilful in responding to the child’s emotional needs, promote independence and self-care, and help the child to share responsibility for their illness and its management.

The ‘Love and Logic’ parenting approach and related material constitute a valuable resource for parents and nurse educators who support them.

V. FOSTERING RESILIENCE
Cultivation of the resilience phenomenon requires an intricate interplay between biological factors (temperament, personality, health, physical ability), psycho-social factors, environmental influences and adversity (emotional and health problems). Resilience comes at great cost but is a tremendous accomplishment that is useful in all avenues of life.

A simplified approach to fostering resilience consists of seven essential building blocks:

1. Connection: Establishing a strong bond between child and primary caregiver in early childhood is important, and should become a springboard to healthy relationships with family members, peers and teachers. Effective communication (both talking and listening) is the basis of satisfactory relationships.

2. Competence: A repertoire of physical, intellectual, emotional, social and practical skills is essential to navigating life’s challenges.

3. Confidence: A child who perceives him- or herself as competent will develop a positive self-image and have
Parents of children with AD have an increased prevalence of poor QOL, anxiety and depression compared to the general population. Poor emotional health in caregivers compromises adherence to therapy, causes exacerbations secondary to transferred psychosomatic distress and increases the prevalence of mental disorders when AD children reach adulthood due to an overprotective parenting style. Moreover, the inadequate management of psycho-social impairment in children may lead to lifelong impairment in physical and mental health.

CONCLUSION

Healthcare providers need to be well informed of evidence-based healthcare protocols for the holistic management of childhood AD and be competent to apply them in clinical practice. This enables us to ensure optimal outcomes in physical as well as psycho-social dimensions of wellbeing in both our patients and their families.

As prudent, compassionate practitioners, we have the responsibility to ensure that our AD patients have the best start in life. In the words of Maria Montessori: ‘In our children lies the fate of our future!’

ACKNOWLEDGEMENTS

A special word of thanks to the brave young artist for her beautiful drawings!

DECLARATION OF CONFLICT OF INTEREST

The author declares no conflict of interest.

REFERENCES