



UNITED KINGDOM

Disease Burden

Prevalence, Diagnosis, and Comorbidities

The prevalence of AD in the UK has been increasing over the past fifty years; 11%–20% of children and 5%–10% of adults in the UK currently are diagnosed with AD.^{18,19}

Not all UK children are equally likely to have AD. The Born in Bradford study showed that children of Pakistani descent were more likely than white British children to be diagnosed with rhinitis, eczema, or wheezing disorders, perhaps indicating an increased AD burden in the UK in this ethnic minority population.²⁰ Ben-Gashir et al. found that although London-born black Caribbean children seemed to have less severe AD than white children at first glance, they actually were almost 6 times more likely to experience severe AD after making necessary adjustments to erythema scores based on skin color.²¹ This finding points to a larger problem: the assessment of disease severity, which is essential for adequate treatment, may be an unmet need that exists in populations with darker skin.

Beyond the considerable impact of AD disease symptoms themselves, the disease burden includes comorbid conditions for which patients with AD are at increased risk. It is well-described that patients with AD are at increased risk for allergic conditions.^{22–24} More recent epidemiologic studies are exploring other comorbid associations; for instance, Arana et al. reported a higher incidence of cancer overall, as well as of certain subtypes such as lymphoma, in patients with AD compared to the general population in the UK.²⁵ Further research is required within the UK to determine the scope of comorbid conditions and to identify any unmet needs related to their management.

¹⁸Simpson, C. R., Newton, J., Hippisley-Cox, J. & Sheikh, A. Trends in the epidemiology and prescribing of medication for eczema in England. *J R Soc Med* 102, 108–117 (2009).

¹⁹Cork, M. J., Danby, S. G. & Ogg, G. S. Atopic dermatitis epidemiology and unmet need in the United Kingdom. *J Dermatolog Treat* 31, 801–809 (2019).

²⁰Mebrahtu, T. F., Feltbower, R. G. & Parslow, R. C. Incidence and Burden of Wheezing Disorders, Eczema, and Rhinitis in Children: findings from the Born in Bradford Cohort. *Paediatric and Perinatal Epidemiology* 30, 594–602 (2016).

²¹Ben-Gashir, M. A. & Hay, R. J. Reliance on erythema scores may mask severe atopic dermatitis in black children compared with their white counterparts. *Br J Dermatol* 147, 920–925 (2002).

²²Hua, T. & Silverberg, J. I. Atopic dermatitis in US adults: Epidemiology, association with marital status, and atopy. *Ann Allergy Asthma Immunol* 121, 622–624 (2018).

²³Silverberg, J. I. & Simpson, E. L. Associations of childhood eczema severity: a US population-based study. *Dermatitis* 25, 107–114 (2014).

²⁴Silverberg, J. I. et al. Association of atopic dermatitis with allergic, autoimmune, and cardiovascular comorbidities in US adults. *Ann Allergy Asthma Immunol* 121, 604–612. e3 (2018).

²⁵Arana, A. et al. Incidence of cancer in the general population and in patients with or without atopic dermatitis in the U.K. *British Journal of Dermatology* 163, 1036–1043 (2010).

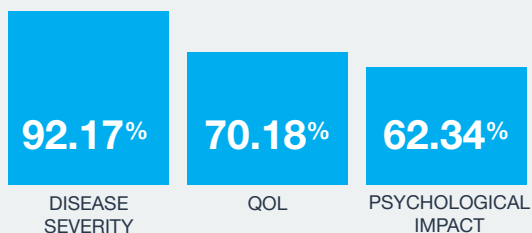
Physical and Psychosocial Consequences

Health utility scores incorporate all aspects of an individual's health state, including physical, mental, and social determinants of health. Health utility scores for UK adults with mild, moderate, and severe AD were 0.985, 0.875, and 0.675, respectively; among UK children, the scores were 0.86, 0.69, and 0.59, respectively.²⁶ The calculated score ranges from 0 to 1, where 1 is a state of perfect health, and 0 is equivalent to death.^{27,28}

Several studies in the UK context have examined psychosocial consequences of AD among both children and adults. In a study of UK children, Dennis et al. found that those with AD were more likely to have psychosocial difficulties compared to other peers of their age. The study also noted that parental psychological health and family functioning were important determinants of whether children coped with AD by internalized emotions, which can lead to anxiety, depression, and social withdrawal.²⁹ Ramirez et al. used the Avon Longitudinal Study of Parents and Children to examine sleep dysfunction among UK children with AD.³⁰ While the total sleep duration was not significantly different between children with and without AD, sleep quality was worse among children with AD across all severities; children with active AD of any severity had almost 50% greater odds of experiencing reduced sleep quality compared to children without AD. Sleep quality was worst among children with severe AD and comorbid asthma, which corresponded to almost 80% higher odds of reduced sleep quality.³⁰

In a study of UK adults, Schonmann et al. used data from the UK Clinical Practice Research Datalink and found that AD was associated with an increased incidence of depression and anxiety. The strength of the association between incident depression and AD correlated positively with disease severity.³¹ Hussain et al. analyzed the association of asthma, AD, and the combination with depression and anxiety symptoms (DAS) in UK adults aged 40–69 using data acquired from the UK Biobank.³² The sample contained 502,641 patients, of whom 13,642 (2.7%) reported AD. PHQ-4 scores were used to evaluate DAS. AD patients on current therapy for their condition were found to have worse DAS than AD patients not on therapy, suggesting that patients with disease severe enough to require regular treatment experience worse QoL outcomes. Additionally, patients who were first diagnosed with AD between ages 40–59 had worse DAS than patients who were first diagnosed between ages 20–39 or 60–69.³²

Disease Severity Mentions in Documented Reports



Although AD clearly has profound impacts on both QoL and psychological well-being, dermatologists may neglect to address these components of disease burden. The British Association of Dermatologists (BAD) and the British Society for Pediatric Dermatology audited documentation from dermatology clinics and compared it to the standards for the management of AD established by the National Institute for Healthcare and Excellence (NICE). The audit found that QoL and psychologic well-being were documented less often than disease severity and treatment regimens.³³ Specifically, disease severity was mentioned at least once in 92.17% of documented reports; QoL was assessed at least once in only 70.18% of the reports, and psychological impact in only 62.34%. Furthermore, compared to 64.64% of reports which contained information about disease severity at every visit, only 29.34% of the reports contained information about QoL at every visit, and only 24.05% of reports contained information about psychological impact at every visit.³³

The study also noted that parental psychological health and family functioning were important determinants of whether children coped with AD by internalized emotions, which can lead to anxiety, depression, and social withdrawal.²⁹

²⁶Stevens, K. J., Brazier, J. E., McKenna, S. P., Doward, L. C. & Cork, M. J. The development of a preference-based measure of health in children with atopic dermatitis. *Br J Dermatol* 153, 372–377 (2005).

²⁷Zhang, P. et al. Health Utility Scores for People With Type 2 Diabetes in U.S. Managed Care Health Plans: Results from Translating Research Into Action for Diabetes (TRIAD). *Diabetes Care* 35, 2250–2256 (2012).

²⁸Silverberg, J. I. et al. Health Utility Scores of Atopic Dermatitis in US Adults. *J Allergy Clin Immunol Pract* 7, 1246–1252.e1 (2019).

²⁹Dennis, H., Rostill, H., Reed, J. & Gill, S. Factors promoting psychological adjustment to childhood atopic eczema. *J Child Health Care* 10, 126–139 (2006).

³⁰Ramirez, F. D. et al. Association of Atopic Dermatitis With Sleep Quality in Children. *JAMA Pediatr* 173, (2019).

³¹Schonmann, Y. et al. Atopic Eczema in Adulthood and Risk of Depression and Anxiety: A Population-Based Cohort Study. *J Allergy Clin Immunol Pract* 8, 248–257.e16 (2020).

³²Hussain, S. et al. Depressive and anxiety symptomatology among people with asthma or atopic dermatitis: A population-based investigation using the UK Biobank data. *Brain, Behavior, and Immunity* 90, 138–144 (2020).

³³Alsharqi, A., Mustapa, M. F. M. & Berker, D. de. UK multicentre audit of the management of eczema in children. *Clinical and Experimental Dermatology* 43, 78–79 (2018).

A study by Girolomoni et al. sought to determine the economic and psychosocial burden in European patients (specifically from France, Germany, Italy, Spain, and the UK) with moderate-to-severe AD.³⁴ In the UK, 29.7% of patients with AD indicated that it affected their QoL – measured by Dermatology Life Quality Index (DLQI) – moderately (DLQI 6-10); 23.9% of patients reported a very large effect (DLQI 11-20); and 33.3% of patients reported an extremely large effect (DLQI 21-30).³⁴ Sleep disturbance, anxiety, and depression rates were also examined in patients with moderate-to-severe AD. In the UK, 30.0% and 8.5% of patients experienced either moderate or severe sleep difficulties, respectively. 61.5% of patients reported anxiety; mild, moderate, moderately severe, and severe depression was experienced by 25.1%, 19.1%, 16.6%, and 15.2% of patients, respectively, as measured by the PHQ-9.³⁴



Howells et al. used the input of patients and caregivers to develop measures of AD “control.”³⁵ Patients and caregivers noted that symptoms of AD may change over time, so a reasonable measure of control involves the return to the patient or caregiver’s definition of “normal.” A common sentiment expressed by patients and caregivers was that self-reporting should be the primary method of assessing one’s control of AD, as each person’s perception of “control” was too unique and too variable to be solely determined by the healthcare provider.³⁵ A patient-centered definition of “control” may focus as much on the psychologic impact, itch/scratch burden, limitations in activities of daily living, and social impact as on the classic signs and symptoms. Ghio et al. considered both objective disease symptoms and the subjective QoL burden and identified three psychosocial needs: to feel understood, to feel “normal,” and for emotional support. The relative salience of these needs appeared to correlate with both the patient’s age and disease severity; university-aged individuals and those with severe disease expressed a greater desire to be understood, while younger individuals and those with mild disease expressed a greater desire to feel normal.³⁶

Sleep disturbance, anxiety, and depression rates were also examined in patients with moderate-to-severe A.D.

Caregiver Burden

An interview-based study by Santer et al. found that the primary source of caregiver burden was the implementation of treatment regimens; topical regimens in particular can take multiple hours to complete over the course of a day. Caregivers felt exhausted by the treatment requirements and guilty if they missed treatments.³⁷ While certainly not unique to the UK, the considerable variance in opinions about evidence-based treatment regimens may result in undertreatment of AD and additional uncertainty and stress for caregivers.³⁸

In light of the difficulty and uncertainty associated with topical regimens, it is perhaps unsurprising that caregivers often search for causes and solutions—most often, diet. Chan et al. surveyed 211 caregivers and adults mostly in the UK and found that 68% of children and 46% of adults with AD were excluding at least one food from their diet; of those, 40% of the children and 52% of the adults were excluding foods specifically to reduce symptoms of AD.³⁹ Of course, diet modifications for children usually require substantial effort from caregivers, and unfortunately, the benefit is unclear—there are no robust data to support any particular dietary intervention for AD.⁴⁰ The lack of robust data leaves caregivers to browse online, where they often feel dissatisfied with the amount of information, quality of information, and uncertainty about financial interests underlying the promoted treatment options.⁴¹

The substantial caregiver burden may manifest in psychosocial symptoms. A longitudinal cohort study conducted in Avon, UK followed new mothers whose child was or was not diagnosed with AD; the study focused on maternal metrics related to sleep quality when the child was aged 6

³⁴Girolomoni, G. et al. *The Economic and Psychosocial Comorbidity Burden Among Adults with Moderate-to-Severe Atopic Dermatitis in Europe: Analysis of a Cross-Sectional Survey*. *Dermatol Ther (Heidelb)* 11, 117–130 (2021).

³⁵Howells, L. M. et al. ‘When it goes back to my normal I suppose’: a qualitative study using online focus groups to explore perceptions of ‘control’ among people with eczema and parents of children with eczema in the UK. *BMJ Open* 7, (2017).

³⁶Ghio, D. et al. *Psychosocial needs of adolescents and young adults with eczema: A secondary analysis of qualitative data to inform a behaviour change intervention*. *British Journal of Health Psychology* n/a.

³⁷Santer, M. et al. *Managing childhood eczema: qualitative study exploring carers’ experiences of barriers and facilitators to treatment adherence*. *Journal of Advanced Nursing* 69, 2493–2501 (2013).

³⁸Santer, M. et al. *Experiences of carers managing childhood eczema and their views on its treatment: a qualitative study*. *Br J Gen Pract* 62, e261–e267 (2012).

³⁹Chan, J. & Ridd, M. J. *Beliefs and practices among adults with eczema and carers of children with eczema regarding the role of food allergy*. *Clinical and Experimental Dermatology* 44, e235–e237 (2019).

⁴⁰Wollenberg, A. et al. *Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part I*. *Journal of the European Academy of Dermatology and Venereology* 32, 657–682 (2018).

⁴¹Santer, M. et al. ‘You don’t know which bits to believe’: qualitative study exploring carers’ experiences of seeking information on the internet about childhood eczema. *BMJ Open* 5, e006339 (2015).

months and then 11 years. Mothers of children with AD reported significantly greater difficulty falling asleep, subjectively insufficient sleep, and daytime exhaustion compared to mothers of children without AD; all these measures were worse in mothers of children with severe AD.⁴² Moore et al. surveyed parents of children with either asthma or moderate-to-severe atopic eczema and found that mothers and fathers of children with moderate-to-severe atopic eczema lost a median of 39 and 45 minutes of sleep per night compared to 0 minutes of sleep lost per night in parents of children with asthma. Of note, sleep disturbance was significantly associated with anxiety and depression scores in mothers and with anxiety scores in fathers.⁴³

Unfortunately, struggling caregivers can have unintentional detrimental effects on their children. In an analysis of 7,250 children from the Avon Longitudinal Study of Parents and Children, Teyhan et al. found that maternal anxiety and depression was associated with a stronger tendency for eight year old children to internalize their symptoms (a proxy for childhood anxiety and depression symptoms).^{44,45}

Financial Burden

The personal financial burden for patients and caregivers in the UK is smaller than in countries such as the US and Australia.⁴⁵ A 2001 study conducted by Emerson et al. found an estimated personal financial cost of £28.94 annually per child; the most common expenses were making changes in the home environment, transportation, over-the-counter (OTC) medications, and consultations with alternative healthcare providers. In one family, consultations with an alternative healthcare provider totaled £625 over a 12-month period.⁴⁶

The Girolomoni et al study also evaluated the economic impact of moderate-to-severe AD. The economic impact was described in terms of work absenteeism %, work presenteeism %, and overall work impairment; all of which were assessed by the Work Productive and Activity Impairment: General Health (WPAI-GH) questionnaire.³⁴ In the UK, rates of absenteeism (absent from work in the past 7 days) ranged from 10.9% for those in the moderate effect DLQI group to 23.9% in the extremely large effect group; rates of presenteeism (AD impacted work performance within the past 7 days) ranged from 29.5% in the moderate effect group to 60.6% in the extremely large effect group; and overall work impairment rates (combining both absenteeism and presenteeism) ranged from 32.3% in the moderate effect group to 67.9% in the extremely large effect group.³⁴

Treatment

Current treatments are often inadequate for severe AD,¹⁹ leading to decreased QoL and negative psychosocial impacts. In a retrospective study utilizing the UK Health Improvement Network, Eckert et al. noted that the unmet need for the treatment of AD manifests in high prevalence of comorbidities such as depression and contact dermatitis. Systemic treatments are available but are associated with potentially significant side effects, though the newer therapy dupilumab is a safer and effective option. Still, a recent study found that 6.6% of patients with AD were requiring systemic steroids or another immunosuppressive therapy and therefore exposed to the side effects that come with these treatment options.⁴⁷

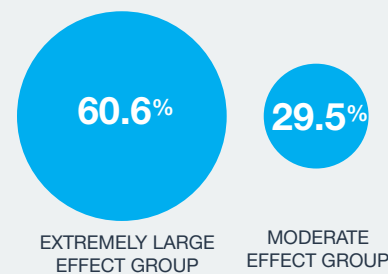
For less severe AD, both emollients and potent topical corticosteroids (TCS) can be highly effective but often are underutilized. Cork et al. found that 24% of children were not being treated with emollients, and 25% of children were not using TCS according to guidelines. Teasdale et al.'s analysis of UK social media platforms found that caregivers were concerned that TCS use might cause harms such as skin damage and withdrawal rash symptoms.⁴⁸ In a survey-based study of



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Rates of Presenteeism

(AD impacted work performance within the past 7 days)



⁴²Ramirez, F. D. et al. Assessment of Sleep Disturbances and Exhaustion in Mothers of Children With Atopic Dermatitis. *JAMA Dermatol* 155, 556–563 (2019).

⁴³Moore, K., David, T. J., Murray, C. S., Child, F. & Arkwright, P. D. Effect of childhood eczema and asthma on parental sleep and well-being: a prospective comparative study. *British Journal of Dermatology* 154, 514–518 (2006).

⁴⁴Teyhan, A., Galobardes, B. & Henderson, J. Child Allergic Symptoms and Mental Well-Being: The Role of Maternal Anxiety and Depression. *J Pediatr* 165, 592–599.e5 (2014).

⁴⁵Herd, R. M. The financial impact on families of children with atopic dermatitis. *Arch Dermatol* 138, 819–820 (2002).

⁴⁶Emerson, R. M., Williams, H. C. & Allen, B. R. What is the cost of atopic dermatitis in preschool children? *Br J Dermatol* 144, 514–522 (2001).

⁴⁷Eckert, L. et al. Treatment patterns in UK adult patients with atopic dermatitis treated with systemic immunosuppressants: data from The Health Improvement Network (THIN). *J Dermatolog Treat* 31, 815–820 (2020).

⁴⁸Teasdale, E. J., Muller, I. & Santer, M. Carers' views of topical corticosteroid use in childhood eczema: a qualitative study of online discussion forums. *British Journal of Dermatology* 176, 1500–1507 (2017).

200 patients with AD, 24% reported non-compliance with TCS due to fears about potential side effects.⁴⁹ Patients may also be reluctant to step up therapy during exacerbations out of fear that the treatments might stop working and they would be left with no alternative.³⁵

Beyond concerns about TCS use, uncertainty about treatment plans explains many instances of poor adherence. Cork et al. found that less than 5% of parents of children with AD remembered having discussions about the causes of AD or the proper treatments for AD. Batchelor et al. identified four treatment uncertainties most commonly shared by patients and healthcare providers: the optimal use of TCS, safety of TCS, food allergy testing, and emollient use in AD.⁵⁰ Meanwhile, patients and caregivers shared uncertainty about psychologic interventions for itching, bathing methods, natural products, irritant and allergen avoidance, diet, and supplements.⁵⁰ For parents caring for infants, Gore et al. identified nine areas in which parents requested more information, ranging from medication use and side effects to treatments and diet.⁵¹



Batchelor et al. identified four treatment uncertainties most commonly shared by patients and healthcare providers: [the optimal use of topical corticosteroids \(TCS\), safety of TCS, food allergy testing, and emollient use in AD.](#)⁵⁰

Prescribing practices in AD may differ between primary care providers may differ from established guidelines.⁵² Santer et al. examined prescriptions for children with AD over a 17-month period and found that less than half of the children received an emollient. 22.8% of patients were prescribed a TCS; 15.9% of these patients received a potent TCS, and 60.2% of patients prescribed TCS received a combination of TCS and antibiotics, suggesting that maintenance therapy could be improved and more judicious use of potent TCS/antimicrobial formulations may be indicated.⁵² In the primary care setting specifically, 44% of patients with AD were not using any emollient, and providers rarely prescribed higher potency TCS for more severe disease.⁵³ De Lusignan et al. reported that potent and very potent TCS were less likely to be prescribed to non-white patients and patients with low socioeconomic status.⁵⁴

Healthcare

Healthcare Utilization

Patients with AD in the UK may benefit from increased access to care from dermatologists and a reduced reliance on primary care providers. Baron et al. found that new adult patients referred from primary care to a dermatologist improved significantly in both the Severity Scoring of AD (SCORAD) and the Dermatology Life Quality Index (DLQI) over the course of three months.⁵⁵ In UK primary care practice settings, only 46% of patients diagnosed with AD actually met the UK criteria for diagnosis. Specifically, providers' assessments had 44% agreement with the Eczema Area and Severity Index (EASI) and 48% with the parent-assessed Patient Oriented Eczema Measure (POEM). Furthermore, primary care providers seem to underutilize both emollients and higher

⁴⁹Charman, C. R., Morris, A. D. & Williams, H. C. Topical corticosteroid phobia in patients with atopic eczema. *British Journal of Dermatology* 142, 931–936 (2000).

⁵⁰Batchelor, J. M. et al. The Eczema Priority Setting Partnership: a collaboration between patients, carers, clinicians and researchers to identify and prioritize important research questions for the treatment of eczema. *Br J Dermatol* 168, 577–582 (2013).

⁵¹Gore, C., Johnson, R. J., Caress, A. L., Woodcock, A. & Custovic, A. The information needs and preferred roles in treatment decision-making of parents caring for infants with atopic dermatitis: a qualitative study. *Allergy* 60, 938–943 (2005).

⁵²Santer, M., Lewis-Jones, S. & Fahey, T. Appropriateness of prescribing for childhood eczema: evidence from a community-based study. *Clinical and Experimental Dermatology* 31, 671–673 (2006).

⁵³Jacquet, L., Gaunt, D. M., Garfield, K. & Ridd, M. J. Diagnosis, assessment, and treatment of childhood eczema in primary care: cross-sectional study. *BJGP Open* 1, bigpopen17X1000821 (2017).

⁵⁴de Lusignan, S. et al. Patterns and trends in eczema management in UK primary care (2009–2018): A population-based cohort study. *Clin Exp Allergy* (2020) doi:10.1111/cea.13783.

⁵⁵Baron, S. E., Morris, P. K., Dye, L., Fielding, D. & Goulden, V. The effect of dermatology consultations in secondary care on treatment outcome and quality of life in new adult patients with atopic dermatitis. *British Journal of Dermatology* 154, 942–949 (2006).

potency TCS for more severe disease.⁵³ Primary care providers are less likely than specialists to view AD as a chronic condition and tend to assign it a less significant priority.¹⁴ Notably, non-white patients and patients with low SES were less likely to be referred to a dermatologist.⁵⁴

The Girolomoni et al study examined rates of healthcare provider visits, emergency department visits, and hospitalizations (all within the past 6 months) among patients with moderate-to-severe AD stratified by moderate, very large, and extremely large impact to DLQI.³⁴ Significant differences in the UK cohort were found in emergency department visit rates (0.25%, 0.47%, and 1.00% in the moderate, very large, and extremely large effect groups, respectively) and hospitalization rates (0.68%, 0.57%, and 1.52%, respectively).³⁴

Satisfaction with Care

Patients and their caregivers may be dissatisfied with care when there are misaligned conceptualizations of the disease, treatment goals, and priorities.

One difference in perspectives involves the nature of AD itself. A study involving 14 general practices across the UK found “several areas of dissonance,” including that parents often searched for an underlying cause, such as an allergen, while GPs sought to manage AD as a chronic condition.⁵⁶ Santer et al. affirmed that caregivers and healthcare providers disagreed about the chronic nature of AD; parents often expressed frustration that diet interventions and allergy testing were not pursued.³⁷ The Chan et al. questionnaire-based study found that 57% of respondents (adults with AD or caregivers of children with AD) had discussed the role of diet in AD with their provider, and 38% of respondents who did were dissatisfied with the conversation.³⁹

Diverging conceptualizations of the disease translate into diverging perspectives on treatment strategies—caregivers focus on finding cures for their child’s AD, while the current treatment guidelines focus on disease control.³⁸ In the aforementioned study of 14 general practices, parents were more likely to view emollients as a passive method of treatment, while GPs viewed moisturization as an active form of treatment. GPs often attributed disease recurrence to poor adherence to topical treatment regimens, while parents doubted the efficacy of emollient therapy and voiced concerns about the side effects of long-term TCS use.⁵⁶ Santer et al. found that caregivers were generally dissatisfied with the information available about treatment options, but they were most dissatisfied with information about the efficacy of emollient therapy and TCS therapy.⁴¹

Despite these diverging views on treatment goals and measures of success, providers expected that patients would adhere to treatment regimens and yet did not prioritize patient education. These “mindlines,” or mental schemas, toward AD were held by experienced providers, indicating a need for further education about the disease burden and current guidelines for evidence-based treatment.¹⁴ The same study investigated the mindlines of patients at a general practice in central England, and four common beliefs emerged: “the doctor knows best,” “it’s not worth bothering the doctor,” “I need to manage this myself,” and “now I know what to do.” The author argued that changing both the mindlines held by providers about AD and mindlines held by patients about doctors and their own AD may lead to improvements in care.¹⁴

Finally, a difference in priorities may lead to dissatisfaction during medical encounters. In the aforementioned study of 14 general practices, parents and GPs took different approaches to severity; parents focused on the psychosocial impact, while GPs focused on the severity of the signs and symptoms.⁵⁶ In an evaluation of the information needs and treatment decision-making roles of parents of children with AD, Gore et al. found that parents of infants with AD often felt their concerns were not taken seriously and had to invest extra effort to receive sufficient information regarding AD from their provider.⁵¹ Santer et al. found that some parents felt that their child’s physician was not dedicating enough time or support to their child’s AD.⁴¹

Santer et al. found that caregivers were generally dissatisfied with the information available about treatment options, but they were most dissatisfied with information about the efficacy of emollient therapy and TCS therapy.⁴

⁵⁶Powell, K., Le Roux, E., Banks, J. & Ridd, M. J. GP and parent dissonance about the assessment and treatment of childhood eczema in primary care: a qualitative study. *BMJ Open* 8, (2018).

Patient-Centered Interventions

Powell et al. advocated for a Written Action Plan (WAP) as a method for clear communications with caregivers. The WAP was developed with the input of caregivers, who preferred plans that were individualized, concise, and clear about the criteria for stepping down and stepping up therapy.⁵⁷

Several interventions have aimed to promote adequate emollient usage. An “educational support program” evaluated by Mason et al. significantly increased emollient use among children with AD and improved several measures of burden: the Patient Oriented Eczema Measure (POEM) scores, sleep disturbances, and parental feelings of control.²⁰ An educational intervention from a dermatologic nurse resulted in an increase in emollient therapy but no increase in TCS use; the intervention was successful at reducing the severity of AD by 89%.⁵⁸ Santer et al. interviewed parents and caregivers of children 5 years of age or younger about eczema therapies and used these responses to develop a web-based intervention. This intervention was then used in another cohort of parents of children 5 years of age or younger with eczema in order to judge the effectiveness of the intervention. Parents and caregivers in the initial cohort believed that emollient use improved AD to some extent but were unsure about long-term effectiveness; all parents surveyed after completing the web intervention believed emollients provided long-term benefit for eczema care.³⁹

Effective education programs seem to be one viable method and may be especially valuable for their ability to ease the financial burden of the disease.

The modest success of these emollient-focused interventions reflects one of the previously discussed components of the caregiver burden: uncertainty about the most effective ways to manage their child’s AD. Effective education programs seem to be one viable method and may be especially valuable for their ability to ease the financial burden of the disease—patients who were prescribed emollients (relative to those who were not) incurred lower per-visit costs, had fewer primary care visits, and required fewer high-potency TCS and antibiotic prescriptions.⁵⁹ Multicenter randomized control trials are likely required to assess the effectiveness of these interventions.⁶⁰

Other interventions have focused more broadly on nurse-led interventions to improve communication and dedicate adequate time to managing a complex disease. In one study, patients seen at a nurse-led clinic were more effective at acquiring prescriptions and finding avenues for additional support for AD, compared to patients seen at only a dermatology clinic.⁶¹ De Vere Hunt et al. examined the impact of a dermatology clinic with dedicated dermatologic nursing and clinical psychologic support on teenage patients with skin disorders. All patients with skin disorders were “very satisfied” or “satisfied” with their care from the doctor or clinical psychologist, and the AD cohort experienced significantly improved Teenage Quality of Life scores (T-QoL) at a follow-up appointment with a consultant psychologist compared to their baseline T-QoL scores.⁶² Finally, in the Eczema Education Programme (EEP) for parents of children with AD, a nurse-led intervention educated parents about disease processes, triggers, appropriate treatment, and strategies for reducing itch and sleep disturbances, all with the goal of improving treatment outcomes and QoL for both the children and caregivers.⁶⁰ Among caregivers who participated in at least two EEP sessions, 98% were satisfied with the EEP; of those, 90% were “very satisfied.”⁶⁰

⁵⁷Powell, K., Le Roux, E., Banks, J. P. & Ridd, M. J. Developing a written action plan for children with eczema: a qualitative study. *Br J Gen Pract* 68, e81–e89 (2018).

⁵⁸Cork, M. J. et al. Comparison of parent knowledge, therapy utilization and severity of atopic eczema before and after explanation and demonstration of topical therapies by a specialist dermatology nurse. *Br J Dermatol* 149, 582–589 (2003).

⁵⁹Moncrieff, G. et al. Cost and effectiveness of prescribing emollient therapy for atopic eczema in UK primary care in children and adults: a large retrospective analysis of the Clinical Practice Research Datalink. *BMC Dermatol* 18, (2018).

⁶⁰Jackson, K., Ersser, S. J., Dennis, H., Farasat, H. & More, A. The Eczema Education Programme: intervention development and model feasibility. *J Eur Acad Dermatol Venereol* 28, 949–956 (2014).

⁶¹Gradwell, C., Thomas, K. S., English, J. S. C. & Williams, H. C. A randomized controlled trial of nurse follow-up clinics: do they help patients and do they free up consultants’ time? *Br J Dermatol* 147, 513–517 (2002).

⁶²Hunt, I. D. V. et al. Establishing and developing a Teenage and Young Adult dermatology clinic with embedded specialist psychological support. *Clinical and Experimental Dermatology* 44, 893–896 (2019).

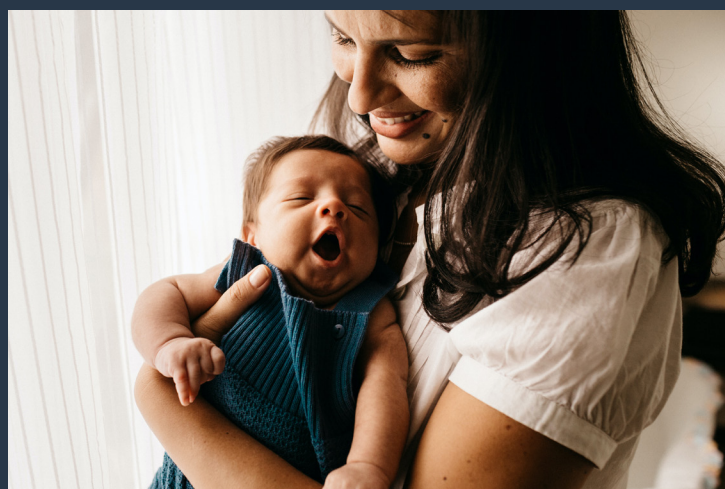
KEY FINDINGS

Patients with AD and their caregivers in the UK experience significant burden due to disease symptoms and psychosocial consequences of AD. Several studies have characterized the QoL and psychosocial burdens, but relatively few studies assessed interventions to mitigate them. Different subsets of the increasingly diverse population in the UK have unique needs regarding AD, and future studies should better characterize these differences to reduce inequalities in diagnosis and treatment based on race and SES. Finally, few studies in the UK have mapped the comorbidities associated with AD; this topic is better studied in the US, Germany, and Denmark.

A misalignment in the conceptualization of AD and treatment goals causes patient and caregiver dissatisfaction with care and suboptimal treatment. Providers tend to focus on visible disease manifestations, but many patients care just as much about improving QoL, reducing itching and scratching, improving sleep, and alleviating mental health symptoms. Survey studies conducted in the UK noted that some patients and caregivers felt these concerns were not evaluated as thoroughly as those pertaining to physical disease symptoms. Furthermore, providers focus on managing the symptoms of AD while caregivers search for a treatable cause, often leading to the pursuit of burdensome dietary changes without demonstrated benefit.

Both parents and caregivers experience confusion regarding appropriate and effective treatment regimens, adding to the caregiver burden and reducing adherence to the evidence-based recommendations for emollient and TCS use. Critically, patients and caregivers have mixed feelings regarding the effectiveness of emollient therapy and the safety of TCS therapy. Educational interventions succeeded at increasing adherence to treatment regimens and improving outcomes. Although the personal financial burden is not as dramatic in the UK as in other countries, the cost of AD treatment still can be significant, and costly alternative therapies for AD may add to this measure of burden. Increasing adherence to emollient therapy as outlined in the study by Mason et al. was found to be both efficacious and cost neutral.⁶³

Several additional interventions have had modest success in the UK by devoting sufficient time to patient education and clear communication, often with nurse-led programs. These preliminary findings suggest that the key to improving patient satisfaction may be thorough strategies like education with continuous reinforcement of key ideas. The ongoing development of additional treatment options for severe disease and more efficacious treatments may significantly reduce the burden, address unmet needs, and increase satisfaction with treatment options and healthcare delivery in the UK.



⁶³Mason, J. M. et al. Improved emollient use reduces atopic eczema symptoms and is cost neutral in infants: before-and-after evaluation of a multifaceted educational support programme. *BMC Dermatol* 13, 7 (2013).