



Psychosocial Considerations in Atopic Dermatitis

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Disclosures

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Objectives

1. Review factors that contribute to psychosocial burden for patients with atopic dermatitis and their caregivers
2. Describe strategies that allergists/health care professionals can use to reduce the psychosocial burden of AD
3. Describe psychological interventions to manage symptoms and reduce the mental health burden of AD





Atopic Dermatitis

- AD is a chronic, episodic skin condition that involves skin barrier dysfunction, immune dysregulation, environmental interactions and genetic factors
- Affects 10% to 15% of children and 7% to 10% of children in the US





Itch-Scratch Cycle of AD



- Itch is a core stressor for patients - aversive sensation that typically elicits involuntary scratching
- Greater itch intensity associated with worse QoL & mental health
- Can disrupt sleep, mood, cause social embarrassment
- Parents describe children as more fussy, clingy and irritable when itchy
- Patients feel ashamed, guilty, angry, frustrated, alone
- Caregivers feel frustrated, helpless, concerned

Kinnert et al., Ann Allergy Asthma Immunol 2018; Chamlin et al., Pediatrics 2004; Patel et al., J Am Acad Dermatol 2019

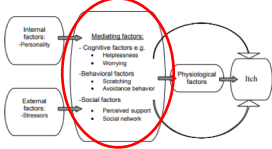


Bi-directional relationship between AD/itch and stress


Body responds to stressful situations/anxiety by increasing production of stress hormones such as adrenaline and cortisol

→ Release of stress hormones can trigger itch
 → Scratching, skin damage, inflammation
 → Helplessness, worry, avoidance
 → More stress and itch

Chronic stress suppresses the immune system, increases inflammation, inhibits skin barrier function/repair



Sanders & Akiyama, Neurosci Biobehav Rev. 2018; Golpanian et al., Clin Ther 2020



Sleep disturbance in patients with AD

- Sleep disturbance is reported by 47-80% of children and 33-87% of adults with AD
- Includes delayed sleep onset, multiple awakenings, reduced sleep efficiency, excessive daytime sleepiness
- High rates of co-sleeping (30%)
- Impact on daytime mood, behavior, neurocognitive function
- Circadian rhythms of the skin, fewer distractions, patient anxiety about falling asleep may all nighttime itch
- Learned behavioral patterns may contribute to continued sleep problems after skin improves

Acquired sleep habits (sleeping, behavioral insomnia)
 Environmental factors (allergens)
 Maladaptive dysregulation
 Nocturnal pruritus due to circadian rhythm of the skin
 Genetic dysregulation (e.g. DRB1, 4, 6, 10, 32)
 Disease flare with itch and scratching

Scratching
 Immune dysregulation
 Chronic stress

Chang & Chiang, J Allergy Clin Immunol 2018; Samyathah et al., Dermatitis 2024; Chang & Chiang, Int J Mol Sci 2016; Silverberg et al., J Invest Dermatol. 2015

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Lifestyle impact

- Students report missing 17 days of school per year and adult missing 11 days of work because of AD
- 43% of adults felt they could be more productive at work if didn't have AD
- Children and caregivers report impact of flares/trigger avoidance on social activities
- AD in children is associated with decreased participation in sports, increased time spent in sedentary activities (TV, videogames)
- In adults with AD, itch is inversely associated with light, moderate, and vigorous physical activity

Zuberbier et al., J Allergy Clin Immunol 2006; Stingeni et al., J Asthma Allergy 2021; Schwartzman et al., Dermatitis 2023; Strom & Silverberg, J Pediatr 2016

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Social stigma and shame

- Self-consciousness about appearance, trying to hide/cover the skin
- Avoidance of being seen in public or skipping social activities during flares
- Difficulty forming intimate relationships/avoid partners seeing body during flares
- Avoidance can further contribute to feelings of isolation

	Patients aged 6-11 years	
	Children	Physicians
These events bother you most	4	4
Relief from treatment is limited over time	4	4
Feeling embarrassed because of AD	4	4
Feeling sad or ashamed	4	4
Get angry and frustrated because of AD	4	4
Avoiding activities you would like to do	4	4
Trouble concentrating in school	4	4
Treatment is unpleasant	4	4
Not being able to mingle with friends because of AD	8	11
Feeling itchy, especially at night	11	11
Being seen in public	13	14
Tensions in the family because of AD	14	14
Missing school because of AD	14	15
Impact on dating choice	14	15
Voluntarily avoiding your friends	14	15

	Patients aged 12-17 years	
	Children	Physicians
These events bother you most	4	4
Relief from treatment is limited over time	4	4
Feeling embarrassed because of AD	4	4
Feeling sad or ashamed	4	4
Get angry and frustrated because of AD	4	4
Avoiding activities you would like to do	4	4
Trouble concentrating in school	4	4
Treatment is unpleasant	4	4
Not being able to mingle with friends because of AD	8	11
Feeling itchy, especially at night	11	11
Being seen in public	13	14
Tensions in the family because of AD	14	14
Missing school because of AD	14	15
Impact on dating choice	14	15
Voluntarily avoiding your friends	14	15

Zuberbier et al., J Allergy Clin Immunol 2006; Ghio et al., Br J Health Psychol 2021; Tosiolo et al., Br J Dermatol 2021

Elmagr Paller et al., Dermatol Ther 2023

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Bullying and stigmatization in AD

- Unwanted comments and unsolicited advice
- Adolescents with AD more likely to experience bullying and cyberbullying than peers without AD
- 39% of children have experienced bullying at school in the previous year
- 34% of adults have experienced discrimination in the workplace
- Avoidance of social situations, social isolation and work absenteeism are more common in individuals with AD who have been bullied

Cheng et al, JAMA Dermatol 2021; Stingeni et al, J Asthma Allergy 2021; Zuberbier et al, J Allergy Clin Immunol 2006

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Handling other children's reactions

- "What's that stuff on you?"
- "Where'd you get it from?"
- "What happened?"
- "Is it contagious?"
- "Ew!"
- "Hey, what's wrong with your skin?"

- They run away
- They won't hold hands
- The looks are worse than the words

National Eczema Association, Child and Teen Expo Session, 2014

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Psychosocial needs of adolescents and young adults with AD

Visible and invisible symptoms

- AYAs with AD experience both visible symptoms (flaky, dry, and inflamed skin) and invisible symptoms (itch, pain, exhaustion and mental distress)
- AYAs struggle with wanting peers and family to take AD seriously while also wanting to be "normal"/ not to stand out or receive unwanted attention
- These concerns may elicit different responses, such as seeking support and avoidance behaviors

Ghio et al., Br J Health Psychol 2021

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Caregiver Burden

- Worry about the next flare
- Fear of adverse effects from treatment
- Helplessness, guilt, "not doing enough"
- Feel blamed/judged
- Sleep disruption—60% wake up 2 or more times/night; worse sleep quality, insufficient sleep, daytime exhaustion (vs caregivers of children without AD)
- Parenting stress
- Social isolation/lack of support
- Increased risk for maternal depression (greater risk for more severe AD)

Capozza et al., Dermatitis 2020; Kim et al., Br J Dermatol 2022; Ramirez et al., JAMA Dermatol 2019; Kang et al., J Am Acad Dermatol 2026

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Treatment burden and barriers

- Gaps in knowledge about AD pathophysiology and treatment mechanisms/goals
- Confusion about treatment plans- which medications to use on which area of the body, how often, how to adjust during a flare
- Time consuming/demanding treatments, fitting into daily schedules
- Child resistance to skincare
- Fear of topical steroid use / concerns about adverse effects of treatment
- Poor acceptability of topicals (slow absorption, stickiness, burning/stinging, odor)
- Social determinants of health and disparities in care – access to specialty care, transportation to appointments, health literacy, income and insurance status, implicit biases based on race/ethnicity that may influence treatment options offered

Trasdale et al., Br J Dermatol 2021; Trasadale et al., Children 2021; Deganoff et al., Pediatr Dermatol 2024; Patel et al., Am J Clin Dermatol 2017; Capozza & Schwartz, Pediatr Dermatol 2020; Maleki-Yozdi et al., JAMA Dermatol 2023; Polakovsky & Chovattaya, Int J Dermatol 2024

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Needle fears and phobias

- Needle fear is common in children and adults
 - 68% in 6-8 years
 - 65% 9-12 years
 - 31% 13-17 years
 - 22% in adults
- Needle phobia (causes impairment/avoidance) – affects 3-5% of the general population, 11-19% of children
- Medication administration commonly reported to be painful
- Fear, pain and apprehension about self-injection may contribute to burden/serve as a barrier to use of biologics
- Research needed to understand scope of this challenge in patients with AD

Toddio et al., Vaccine 2022; Orenius et al., SAGE Open Nurs 2018; Coyne et al., Patient Prefer Adherence 2022

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Adolescent and young adult understanding of AD

- Caregivers often receive information about AD management when children are young
- AYAs may not receive this information again as they get older
- AYAs with AD since early childhood report confusion about AD cause and treatment, may create routines based on their experiences/teaching from parents vs. directly from healthcare professionals
- AYAs gradually shift expectations from "cure" to "control" of AD

"They should be telling you exactly what your condition is, as if it was from new to start off with. Because the understanding's different now ... But they just believe that as a child you understood and you've carried on. You need to apply your creams because it's your routine. But you don't understand like what the creams are and what they're doing."
- Adolescent with AD

de Vere Hunt, BMJ Open 2021; Lundin et al., BMJ Open 2021; Ghio et al., Br J Dermatol 2020; Kasser et al., JAMA Dermatol 2018

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Adolescent and young adult experiences with AD management

Common challenges

- Lifestyle factors (busy schedule, sports, social events)
- Desire for autonomy may be at odds with need for parental support
- Caregiver control for management → help with planning, organization (won't be "perfect" at first)
- Healthcare transition
- Navigating management at college/work/shared living situations
- Finding reliable information online

Greenwell et al., BMJ Open 2021; Coyne et al., Health Expect 2025

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Financial stress and burden

- Cost of co-pays/deductibles for health care visits and prescriptions
- Out of pocket costs for over the counter emollients and treatments
- Work absenteeism and reduced productivity for adult patients
- Caregiver absenteeism, reduced work hours or decision not to work due to burden of caring for the child – greater impact for mor severe AD

Smith Begallo et al., Dermatitis 2021; Drucker et al., J Invest Dermatol 2017; Capozza et al., Eur Acad Dermatol Venereol 2022

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Mental health burden

- Patients with AD are at increased risk for depression and anxiety
 - >2-3 x greater risk for adults
 - >1.5 x greater risk for children and adolescents
- Adolescents and adults are at an increased risk for suicidal ideation
- Mental health risks increase with greater disease severity, more poorly controlled disease, and sleep disturbance (after controlling for severity)

Romstedt et al., J Am Acad Dermatol 2019; Kis et al., Front Psychol 2019; Siewersberg et al., Br J Dermatol 2019; Samaha et al., JAMA Dermatol 2019; Zhu et al., BMC Psychiatry 2026

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AD mental health risk pathways

- Burden of inadequately treated disease – in clinical trials, substantial decrease in depression and anxiety with improved skin control; patients report their mental health is most affected during flares
- Sleep disruption – effects on brain development, behavior, mood, attention
- Inflammation – may play a role in pathophysiology of depression/anxiety
- Psychological factors – catastrophizing thoughts, perceived lack of control, avoidance of pleasurable/valued activities
- Impact of mental health comorbidities on AD control – anxiety triggers more itch, affect of depression on adherence

LeBovidge & Schneider, Ann Allergy Asthma Immunol 2025; Rodtke et al., Pediatr Dermatol 2023

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Normalizing, validating and understanding patient support needs

- HCPs may not consistently ask about psychosocial burden during AD visits, and stigma about mental health care may discourage patients from introducing such concerns
- Normalizing and validating experiences/emotions helps reduce stigma and isolation

“Having AD and following treatment routines can be stressful. Is it okay if I ask you some questions to understand how AD has affected you?”

- What is going well with AD management? What is most stressful/challenging?
- What parts of your routine do you miss the most? What gets in the way?
- Does AD make it harder to sleep at night?
- Are there times that you miss out on things that are important to you because of AD?
- What do you wish more people understood about AD?
- How can I support you in handling these challenges?

Chatrath et al., Skin Health Dis 2024; Foster et al., JAAD Int 2023; LeBovidge & Schneider, Ann Allergy Asthma Immunol 2025

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Promote a team approach to managing itch

“Stop scratching” → Shame/frustration/helplessness → More scratching

- Build self-compassion: It’s very difficult not to scratch when you are itchy and caregiver frustration is normal!
- Focus on what patient/family CAN do instead of scratching to make the child feel more comfortable and in control
- Praise patients for use of coping strategies to manage itch

“It looks like your eczema is bothering you, let’s do something to help you feel better.”
“Sometimes my skin will flare, but I know steps to treat it and feel better.”

Klinnert et al., Ann Allergy Asthma Immunol 2018

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Building a toolbox to manage itch

- Focus on what patient/family CAN do:
 - Quick relief to soothe the skin: moisturizer, cool pack, cool compress, firm pressure
 - Keeping hands busy: drawing, fidget toy, Legos, stress ball, origami, instrument
 - Distraction: game, ride bike, music, reading, funny movie, talk with friend
 - Relaxation strategies
- Plan ahead for specific situations/triggers:
 - Pad and pen to doodle while watching TV
 - Small fidget toy and moisturizer at school
 - Water bottle and cooling towel for soccer game
 - Special toys for car rides (when harder to manage scratching)
- Remind parents to praise behaviors they want to see more often

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Improving sleep for patients and families

Take an empathic, non-judgmental approach – families are desperate for sleep & choices around bedtime routine are typically the result of vs. cause of sleep problems

Effective AD management may result in improvements in not just skin health but also sleep duration, efficiency, nighttime awakenings, and mood on waking.

- **Good skincare**
 - Manage itch
 - Help the skin heal at night
 - Consider wet wraps, covering skin
- **Sleep hygiene/routines**
 - Consistent bed/wake times
 - Relaxing routines ending in bedroom
 - Avoid screens
 - Cool, dark room
- **Referrals as needed**
 - Sleep specialist, mental health provider
 - Behavioral treatment for sleep onset problems, nighttime awakenings
 - CBT for Insomnia

Mindell et al., Sleep Health 2023; Meltzer et al., Ann Allergy Asthma Immunol 2020

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Using mind-body relaxation skills

Mind-body relaxation skills can help the nervous system return to a state of calm to break the stress-itch cycle, refocus attention away from itch, help with sleep onset


Belly breathing – using your breath to trigger the relaxation response

Imagery – using the imagination to create relaxing or soothing imagery, using all of your senses. The body responds as if you are in the scene you are imagining

Mindfulness – using your senses to focus on what is happening around you, what your body is doing and how you are feeling in the present moment, without judgement

Practicing relaxation skills is like learning to play a new sport or instrument- encourage patients to practice when they are not very itchy or stressed

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Resources to share with patients and families

YouTube videos for young children

- Breathe with Me – Guided Breathing Meditation for Kids (also a book)
- Sesame Street Belly Breathing with Elmo
- Sesame Street Belly Breathing with Rosita
- Sesame Street Good Night Body with Elmo

Books for young children

- Breathe with Me: Using Breath to Feel Strong, Calm and Happy* by Miriam Gates
- My Magic Breath: Finding Calm Through Mindful Breathing* by Nick Ortner and Alison Taylor

Websites for older children/teens


- Guided meditation exercises for children (website): <https://annakaharris.com/mindfulness-for-children/>
- Mindfulness for teens (website): www.mindfulnessforteens.com

Apps for older children/teens

- Breathr (free)
- Smiling Mind (free)
- Breathe2Relax (free)
- iSleep Easy (free)
- Rain Rain (free, sound for relaxing and sleeping)

You can also find relaxing sounds, meditation music, bedtime stories on Alexa, Toniebox, etc.

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Self-esteem: addressing the visible and invisible

- Listen, validate
- Ask about bullying/teasing/unwanted attention from others
- Ask about positive support from family and friends
- Practice answering questions about AD, what patient wants/needs others to know
- Reinforce/provide support for participation in valued activities the patient enjoys that may be impacted by AD (sports, social activities)

Give it a name and set the tone. AD is not something to be ashamed of.

"It's called eczema. It's dry, itchy skin."
"It's like an allergy. You can't catch it."

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Make plans for doing what's important

Soccer


- Water bottles to stay hydrated
- Cooling towel if I get itchy/hot
- Change of clothes for after game
- Shower when I get home
- Tell my coach ahead of time so they understand

Sleepover

- Shower/skincare before I go
- Extra cream
- Cotton Pjs
- Clean pillow/sleeping bag
- Other parent/friend knows about my eczema
- Can switch to a "sleep under"

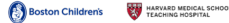
School

- Fidget in desk
- Moisturizer in backpack
- Secret signal for nurse/meds
- Wipe down after PE
- Counselor as needed



Information for Teachers

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Addressing bullying

Signs of bullying can include:

- Changes in behavior/mood
- Not wanting to talk about or participate in social activities
- Not wanting to go to school
- Decline in grades
- Frequent visits to the nurse
- Sleep problems
- Frequent headaches of stomachaches
- Change in eating habits
- Unexplained injuries

How to provide support


- Listen/find out what is going on
- Give the message you want to help.
- Let the child know that the bullying is not their fault
- Tell the school what is going on
- Help the child identify a safe person at school who is available/willing to advocate
- If needed, ask for separation f the bully from the child (victim should not be singled out)
- Consider referral to school counselor, mental health professional

Steps kids can take

- Look at the person and tell them to stop in a calm/clear voice, if this feels safe
- Walk away. Separate yourself, don't give the bully more "gas."
- Don't fight back – this could lead to getting hurt/in trouble.
- Talk to an adult you trust. It's not tattling, it's reporting something that is wrong. Adults can help make a plan to stop the bullying.
- Stay near adults and supportive peers. Most bullying happens when adults aren't around.


www.stopbullying.gov

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Reducing treatment burden

- Use/review written action plans & simplify routines when possible
- Provide developmentally-tailored education
 - Brick and mortar analogy
 - Baths are like a "drink for thirsty skin" so skin won't feel as dry
 - Moisturizer makes your skin strong – superhero getting stronger!
 - Medicine helps keep the rash and itch away – put the fire out!
- Make the routine fun
 - Bath toys, bath book/music, "spa time"
 - "Painting" on the skin with moisturizer, "frosting a cupcake"
 - Game/story while topicals/moisturizer soaks in
- Acceptable choices to increase control (arm or leg first?, story or game after skincare?)
- Medical play – wrap stuffed animal, give doll a bath, moisturizer to parents' skin




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Goals for pokes/injections


Getting the medicine/procedure the child needs to be healthy
AND
 Feeling safe and comfortable
 Feeling proud and confident



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Preparation for pokes and injections

- Provide simple explanations of how treatment helps
- Remind parents to model calmness
- Young children often benefit from medical play (e.g., practicing on a doll or stuffed animal, using real or pretend equipment) to build familiarity and identify misconceptions
- Parents can create a coping story or checklist with the steps of the visit/procedure and practice at home




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Coping skills to decrease anxiety/increase comfort

Printable Comfort Poke Plan

- Shift mindset from threat thinking (“this is terrible/I can’t handle it”) to brave coping thoughts (“this might be uncomfortable, but I can do brave/important things”)
- Keep verbal warnings brief - less waiting time with quick treatments usually best
- Turn down the pain signal –ice pack, numbing cream, vibration (Buzzy)
- Belly breathing
- Hold a stress ball, comfort item, parents’ hand
- Distraction (video, music with headphones)
- Special treat/activity afterwards



Meg Foundation: <https://www.megfoundationforpain.org/>

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Resources for managing poke/injection fear and pain

- **Meg Foundation** - <https://www.megfoundationforpain.org/>
 – Many resources for managing pain and medical anxiety, including a printable “Poke Plan” and a Comfort position handout for pokes/injections
- **BCH Family Medical Coping Initiative (FMCI)**
 – <https://www.childrenshospital.org/programs/family-medical-coping-initiative>
 – FMCI webinar (linked on their website) specifically focused on helping children prepare for vaccines and other pokes
- **ImaginAction**
 – <https://imaginaction.stanford.edu/>
 – A collection of audio recordings that support coping and self regulation skills
 – Guide specifically for supporting calm during pokes/procedures:
<https://imaginaction.stanford.edu/calm-during-procedures-and-pokes/>

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Trusted education and support resources

You can’t do it all in one visit!

- Boston Children’s AD handbook
- National Eczema Association: nationaleczema.org
- Global Parents for Eczema Research: gper.org
- Support for Eczema Caregivers Program: gper.org/caregiver
- EczHale Eczema Mental Wellness Hub: gper.org/eczhale
- AAD Camp Discovery: campdiscovery.aad.org
- CSDP Camp Wonder: www.csdp.org



ECZHALE | Childhood Eczema & Mental Wellness Hub



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Patient-Reported Outcome Measures (symptom severity, control)

POEM for self-completion and/or proxy-completion score

Most recent score: **37 (Greater eczema)**

Over the last week, on how many days has your/your child’s skin been itchy because of the eczema? **5-6 Days**

Over the last week, on how many nights has your/your child’s sleep been disturbed because of the eczema? **5-6 Days**

Over the last week, on how many days has your/your child’s skin been bleeding because of the eczema? **No Days**

Over the last week, on how many days has your/your child’s skin been weeping or oozing clear fluid because of the eczema? **No Days**

Over the last week, on how many days has your/your child’s skin been cracked because of the eczema? **3-4 Days**

Over the last week, on how many days has your/your child’s skin felt dry or rough because of the eczema? **Every Day**

Over the last week, on how many days has your/your child’s skin been flaking off because of the eczema? **Every Day**

Total Atopic Dermatitis Control Tool (ADCT) Score

Most recent score: **33 (Atopic Dermatitis may not be well controlled)**

Over the last week, how would you rate eczema-related symptoms? **Moderate**

Over the last week, how many days did you have intense episodes of itching because of the eczema? **1-2 days**

Over the last week, how bothered has been by their eczema? **Moderately**

Over the last week, how many nights did have trouble falling or staying asleep? **5-6 nights**

Over the last week, how much did eczema affect their mood or emotions? **A little**

Over the last week, how much did eczema affect their usual activities? **Moderately**

Patient-oriented eczema measure (POEM): Charman et al., Arch Dermatol 2004

Atopic Dermatitis Control Tool (ADCT): Pariser et al., Curr Med Res Opin 2020; Lee et al., J Am Acad Dermatol 2025

Harmonizing Outcome Measures for Eczema (HOME): homeforeczema.org

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