

GlobalSkin Position Paper



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International Alliance of
Dermatology Patient
Organizations

Atopic Dermatitis: A Collective Global Voice for Improving Care

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Cover photo: Participants of the Atopic Dermatitis Round Table meeting in September 2017.

Introduction

Atopic dermatitis (AD) is the most common form of eczema. It is currently an incurable, chronic immune-mediated systemic disease with a debilitating effect on individuals and families worldwide. Atopic dermatitis is more than ‘just a skin condition’. People living with atopic dermatitis feel its effects – both on their skin (with a relentless itch, redness, swelling and lesions) and on their well-being (linked to sleep deprivation, social isolation, anxiety and depression, and an overall reduced quality of life). Patients with inadequately controlled atopic dermatitis face the devastating and unpredictable physical and psychosocial impact of the disease, every day. The backgrounder found at Appendix B contains more detailed information on AD.

This Position Paper has been developed following a round table meeting of clinicians, researchers and patient leaders from national and global organizations, together representing the global AD community (see Appendix A for list of participants). It was organized and hosted by the International Alliance of Dermatology Patient Organizations (IADPO), supported by a joint unrestricted educational grant from Sanofi Genzyme and Regeneron.

The goal of the meeting was to bring together a united, international voice to help support patients with AD; to discuss the issues affecting patients and the AD community; to better understand the gaps in care; and to identify advocacy priorities where the community can collaborate to drive change for patients and families locally and globally.

This paper seeks to identify the gaps and challenges in atopic dermatitis and to provide an incentive for the gathering of evidence and collaboration amongst stakeholders to positively impact quality of life for those living daily with AD.

Executive Summary

Patients with AD experience a complex range of challenges in their daily lives which go above and beyond the painful and visible manifestations of their disease. Symptoms can be extremely debilitating and difficult to control. The reasons for this vary from patient to patient and depend to some extent on the resources available to them.

Currently, finding effective treatments is a challenge for patients, if they even exist. Frequently the associated side-effects and time-consuming protocols can act as a deterrent to prescribing by the physician and adherence among patients.

Mental health challenges are also part of the patient experience with moderate-to-severe cases of the disease. Patients face stigma in society, social isolation, and can even have a clinical diagnosis of depression and anxiety. The powerlessness to control their disease brings an additional burden as frustration grows over the loss of control. Personal relationships can be strained, and caregivers can carry a heavy practical and psychological burden themselves.

Atopic dermatitis is not considered a priority for health systems and therefore is universally poorly resourced. This has a number of negative consequences for the quality of care for patients, including: inadequate training of first line physicians, a limited number of treatment options for doctors to offer, and a lack of time that doctors are available to spend with their patients. Given high levels of frustration by patients and physicians who have limited time and options to help, the doctor-patient relationship suffers, and poor communication adds to the frustration that patients and providers feel.

This Position Paper sets out the challenges facing the AD/Eczema community and the barriers to securing greater policy attention. This includes a lack of data on the burden of disease and low public awareness. The assembled round table participants recommended a seven-step plan to address this unsatisfactory picture for patients, with the goal of securing greater attention to this disease among all stakeholders and ultimately better outcomes for patients. In brief, these steps include:

1. Call for international collaboration amongst all stakeholders, led by patient leaders and the International Alliance of Dermatology Patient Organizations (IADPO)
2. Generation of credible evidence on prevalence, economic costs and impact of disease
3. A global campaign to raise awareness of the disease and its true impact
4. Empowerment of patients via improved access to information and support, as well as tools to help in consultations with their physicians
5. Improved care for patients from both family doctors and specialists so that care is holistic, accessible and includes access to psychological support
6. Sharing of best practices and guidelines to improve quality of care universally
7. Continued investment into and timely access to innovative solutions and treatments for disease control.

While there are a great many challenges facing the AD/Eczema community, it is clear that working in a coordinated, strategic manner – via an alliance of patient organizations, together with key stakeholders – will provide the best chance of bringing about positive change.

Living with Atopic Dermatitis – The Challenges

The AD Round Table of experts and key opinion leaders (listed in Appendix A) shared what they believed were the biggest challenges for people living with moderate-to-severe atopic dermatitis:

1. The vicious circle of physical symptoms

Patients with AD experience considerable physical pain and distress. The chronic itch can be completely unbearable. As well as residual pain in the skin, there can be problems with pain in joints and the feet. Pain tends not to be well-managed, especially in moderate-to-severe AD. The relentless 'itch-scratch cycle' is common among AD patients - the more one scratches, the worse the itch becomes, and the guiltier patients report feeling because of their inability to stop scratching. Sleep deprivation and chronic fatigue are common among patients with AD. Many also have other known 'atopic' co-morbidities like allergic asthma, urticaria, allergic rhinitis, food allergies and psychiatric illnesses.

2. Mental health

Anxiety and depression are common among people living with AD. Embarrassment and shame are common feelings. There is an overall feeling of not being in control, despite often meticulous attention to care and treatment regimens. The uncertainty and inevitable relapses caused by not being able to control triggers is reported as being overwhelming.

Like other skin diseases, AD is both stigmatized and minimized. It significantly restricts patients' social involvement, which can contribute to AD's psychological burden. Some people whom patients encounter may not want to stand close to them or share a swimming pool, while others will tell them that AD isn't serious or worthy of concern because it's "just a skin rash." Patients therefore are doubly shamed and feel alienated and misunderstood when they are ostracized and yet also told they shouldn't feel bad (when they express that living with AD is difficult).

3. Access to services

In many countries, there is generally inadequate training in dermatological diseases for primary care physicians. Additionally, in most cases, there is poor access to specialist dermatologists/allergists/immunologists – either because of a lack of capacity or because of inadequate referral pathways. Even when a patient does get to the correct specialist, which can take months to years, it is estimated that globally doctors have on average only ten minutes to spend with them – a problem reported in many countries.

Some patients report that given poor access, they simply give up, resigned to life with a debilitating illness.

4. Treatment

There is a body of evidence to suggest that many adults with AD downgrade their need for treatment and 'over-cope' with the disease. Patients may say that they are not itching much but their partner observes a bed 'full of blood'. AD can be a very time-consuming condition to manage. Patients can spend over an hour each day on their treatment regimens.

The pattern of usage of different therapies is dependent on many factors and varies enormously from country to country, and even from region to region within a country. Reimbursement systems also

differ widely and in some countries patients face a considerable financial burden or have very limited treatment choices. Sometimes even when physicians are aware of a treatment that might be more effective for the patients, the therapy will remain unmentioned if there is no financial/reimbursement coverage of the medication, or if treatment requires burdensome insurance paperwork and health monitoring by the physician. In most cases, patients must pay for many over-the-counter and supportive medicines. In Australia for instance, it is estimated that the annual out-of-pocket costs to patients with atopic dermatitis is A\$2000 per year. In the UK, therapies such as creams and emollients are likely to be removed from reimbursement as a means to cut costs to the health service. This will mean that AD patients will have to pay for much of their treatment out of pocket.

The side-effects of some treatments (e.g. immunosuppressants, corticosteroids) can, for some patients be more detrimental than living with the symptoms alone. Due of the lack of treatment options and the side-effects and safety profiles of currently available therapeutic options, some patients turn to alternative therapies that have limited scientific evidence, but can provide both physical and psychological benefit. They report that doctors are too focused on drug treatment overall and do not devote enough time to other strategies to help control triggers. Physicians do acknowledge this and blame the lack of time they have for consultations.

5. Information and communication

It is widely agreed that there is a shortage of reliable information for patients and family members regarding AD. While written information is important, patients face the problem of knowing what information they can trust on the internet. In-person support would also be beneficial to many patients. Coaching on how to manage treatment regimens is particularly valuable and helps build confidence and mastery of a condition. In the UK, Allergy UK invited specialist nurses to show parents how to apply topical therapies to their children and received excellent reviews. Unfortunately, there are no resources to roll this out widely in the UK. While there are some patient and family education programs undertaken by either local patient associations or in clinics by nurses or physicians, these are highly localized and generally sporadic. One main barrier is the ability to make patients/caregivers aware of the resources available to them.

Many patients with this chronic disease become experts in their own right seeking resources and education from a host of sources beyond the physician's office. Some patients report feeling that their dermatologists are unwilling to listen to their opinions, fears and frustrations with adherence to care regimens or to discuss the more psychological aspects of the disease. Ideally the discussion should be two-way and while this is acknowledged by health professionals, they say that the pressure of time, and a lack of resources are to blame for this mismatch between patient expectations, physician role expectations and system capacity which exists in most countries.

6. Limiting life choices

Atopic dermatitis can impact the choices people make about academic studies and vocations. Patient groups often hear of cases where patients have had to cut short their careers, or change vocational direction midstream when eczema flares have impacted their ability to perform their duties. For example, those whose hands are affected by AD may find it difficult to engage in frequent hand washing or wear latex gloves which would make a role in nursing impossible; those who wish to work in customer service roles such as retail can lose their jobs because of customer reactions to their unsightly skin. Individuals who are working and suffering from AD are more likely to take time off work (and school) during flares. Children may be bullied, teens may be ostracized and have issues with school attendance as a result. While absenteeism is a visible barrier to success, presenteeism can also be a problem, therefore also limiting upward mobility in careers.

7. Relationships

Patients widely experience a sense of isolation, and are unable to enjoy a full social life because of their disease. Intimacy can be affected, both adult to adult and adult to child (parents with AD tell of their children being afraid of their skin). People living with AD tend not to like having their skin touched so partners need to learn what might feel good and be acceptable, and what isn't. Atopic dermatitis can also profoundly impact sexuality, dating, marriages and even the decision to plan pregnancies. While there is currently limited data on divorce rates, anecdotally patient organizations have noted that it may be quite significant.

8. Impact on caregivers and families

For those caring for a loved one with atopic dermatitis, the disease can also be a serious burden. Sleep deprivation is common for both the patient and family members in the household. Caregivers report depression and anxiety, tiredness and feeling emotionally drained. Family members, including siblings, sometimes experience feelings of resentment. Coping with the disease also imposes a high practical burden through the need to manage the home environment: the washing, vacuuming and keeping everything dust-free.

Families and caregivers spend considerable time and energy learning what triggers bring about flares, and then shifting and changing diet, detergents, air filters, etc., to help reduce the onset of the next dreaded flare.

Children with eczema might be treated differently from their siblings and behaviours, resentments and complex interactions can develop. Children with the condition become the centre of the family's attention. The family dynamic is altered – AD becomes a burden for the entire family.

Treatment and Care in Atopic Dermatitis

In general, patients with AD can have difficulty navigating their care system and often are not able to see a specialist in a timely manner, delaying treatment and optimized outcomes. Clinicians acknowledge there are gaps in care and no universal agreement on management of the disease.

1. No consensus on care

Typically, step-up also known as ‘stepped’ treatment regimens start with a baseline trigger avoidance, emollient therapy followed by topical corticosteroids (TCS) or topical calcineurin inhibitors (TCIs), phototherapy, and then, lastly, systemic therapies. Although the value of clinical guidelines is sometimes debated, it is felt by the round table panel that the absence of agreed standards is adversely impacting care quality. There is considerable variation in how doctors treat the disease across countries and even within them.

2. Disease severity/classification

While there are several published and validated tools to evaluate disease severity and activity, few view the patient ‘holistically’ – taking into account the full impact of the disease; the signs, symptoms and quality of life aspects. These tools are mainly used to assess disease severity in clinical trials and are inadequate for clinical practice. As a result, there is no universal or consensual means by which physicians assess mild, moderate or severe AD. It was felt this lack of clarity amongst health professionals is another reason why patients often don’t receive effective treatment. Itch is currently the main factor driving disease severity, but this is highly subjective and difficult to measure. While physicians typically assess severity based on itch, physical lesions, and treatment history, it would seem that they can often overlook patient reported insights and may not be able to take the time to consider the impact AD has on the quality of life of their patient and their extended family.

3. Treatment Options

‘Treatment can be worse than living with disease’. Treatment options that are currently available in many countries may only provide sub-optimal treatment results. In addition to this, where the treatments are prescribed to patients, non-adherence is common, due to the lack of education, time-consuming regimen or side effects.

Patients also report that their doctors are too focused on drug treatment and they would also like to spend more time discussing other strategies for controlling their triggers.

4. Doctor-patient interaction

Poor quality interaction between patients and their doctors limits the opportunity for improved patient outcomes. A lack of self-esteem can inhibit a patient’s ability to communicate with their doctor, and they can often find it difficult to explain the intensity of their symptoms or the impact AD has on their overall quality of life, including sleep, ability to conduct daily activities and its long-term impact on intimacy and life-choices, etc. Patients sometimes report that their doctors do not listen to them properly. Physicians recognize that adult patients have a tendency to ‘over cope’ with the disease which also inhibits optimal conversations and recourse to care.

5. Continuity of care

Patients with AD will commonly have other associated conditions. However, they report that the health care professionals they see in different specialties do not share their medical information with each other nor collaborate and this adds to the frustration with treatment. Treatment is taking place in silos rather than holistically which may undermine patient outcomes.

6. Training for physicians

In many countries, general practitioners receive very little dermatological training. This can result in inappropriate treatment, delayed referral to specialist care and a lack of recognition of the importance of atopic dermatitis in healthcare provision. In addition, in many countries payment and incentive systems for physicians tend not to be set up to encourage more focus on skin conditions.

System and Societal Factors

People in general are familiar with eczema but do not understand that there are many types of eczema and that atopic dermatitis is the most common form. Like all skin conditions, atopic dermatitis has different degrees of severity with the moderate-to-severe forms often having a debilitating impact on the life of patients.

1. Public awareness and stigmatization

Because skin conditions are not considered ‘serious diseases’, there is a shortage of general health education about them and therefore little public awareness of what these illnesses mean for those living with them. Despite some awareness of the existence of eczema, there is considerable public ignorance about AD. This means there is a lack of public discourse and no consideration of AD as a health priority. The lack of understanding has significant implications for stigmatization. If there were more open discussions on the issues, and an understanding of the non-communicable aspect of the disease, then the understanding and compassion would grow with the increased awareness of what it is really like to live with AD.

2. Evidence and research

There is a great shortage of resources and incentives in the health system locally and globally to encourage more research into the epidemiology of AD and its costs to health services delivery and to society at large. Without a better research base, attempts by the community to influence policy are quite constrained.

3. Policy

Most health policy attention is devoted to the common ‘killers’ like cancer and prominent non-communicable diseases such as diabetes and cardiovascular disease. Generally speaking, society does not adequately value the management of other chronic conditions like AD. It follows that there is a lack of interest in policy development to support improved care of AD, yet without greater policy influence, the AD community will continue to find it difficult to attract greater health system investment in improving AD care.

4. Resource provision

Certain disease areas are given so much importance, that others lose out and become ‘Cinderella conditions’. Because people don’t die directly from AD, and in most parts of the world where there is a culture of ‘grin and bear it’, it is the patient’s personal burden and patients are simply expected to ‘manage’. Because patients tend to isolate themselves and feel shame, they are less likely to self-advocate or even seek out others to build a movement for change. When patients themselves are reluctant to step forward, there is a lack of advocacy, and without pressure there is a lack of interest on the part of policy makers. It does not help that there is a lack of data to assist in making the case for a higher priority to be assigned. Estimates suggest that up to 27% percent of the US population have some form of skin condition, and that 6.6% of the European Union population have skin problems, with significant differences between countries. But overall there is a poor evidence base to make a compelling case for change, and so people living with dermatological conditions like AD, suffer, usually in silence. However, many patient advocacy organizations are making headway against this challenge.

Unfortunately, this is a common issue for skin problems which is exacerbated by under-investment in services. For a number of reasons, dermatology is relatively under-resourced in many countries. Fewer dermatologists mean longer wait times and shorter appointments. This has a direct impact on patient care with dermatologists around the world reporting that they only have the capacity to spend ten minutes on-average with each patient. The lack of resources dedicated to dermatology also has implications for research, the policy agenda and the ability to tackle public awareness.

Advocating for Change – the Journey to Better Patient Outcomes

The illustration below is intended to show the journey that the AD community needs to embark upon in order to realize better outcomes and a chance at improved quality of life for patients in the future. There is a lack of good data to evidence the true burden of the disease and therefore to make a compelling case to policy makers for greater priority to be given to AD. If real world evidence can be gathered and communication strategies can be built around the evidence – which would take several years to accomplish – momentum can build for further change through a growing awareness of the condition among the general public. This could in turn further draw the attention of policy makers and those responsible for the overall management of local medical systems to the needs of patients living with AD. This consequently provides a much greater incentive for pharmaceutical companies to invest in research for much-needed innovative new treatments. This is already being done in the US with researchers and patient organizations collaborating to change the tide.



Stronger Together – A Proposed Seven-Step Plan to better support people living with atopic dermatitis

1. Collaboration

IADPO has initiated the process of bringing stakeholders together to develop and implement an international plan of action to improve the lives of people living with AD. It is also considered important that while led by patients, the community brings patients representatives and health care professionals together so that a strong and united voice can be presented to Governments in making the case for the measures addressed in this position paper.

2. Evidence generation

At present the community does not have a true picture of the scale of the AD disease burden at national or global levels. Strong and credible impact of disease data are needed. Prevalence data, alongside research into the economic costs of the disease (such as the cost of absences from work through illness) are also needed in order to develop a rigorous evidence base for policy development. It is approaches like this that will help make the case that investment in better care will be cost effective.

3. Public awareness

Without greater public awareness and debate on AD, it is difficult to secure a place for the disease in government health priorities. By having IADPO build a community of interested stakeholders and present a united front, this can be tackled. As yet there has never been a global campaign on AD although there are good examples of work in other disease areas from which the AD community can learn. The power of a unified global message that speaks to the impact of the disease can be leveraged by all local organizations to strengthen their communication and advocacy.

4. Patient empowerment

There is a consensus that significant information gaps exist for patients and that this needs to be addressed through a number of different tools and techniques. In a perfect world, patients are powerful self-advocates, coached to be confident navigators of their countries' systems. This model has been adopted in the US. Unfortunately, not everyone is equipped to do this and the non-validation of the impact of AD on a patient's life by the healthcare system and society contributes to the status quo of subpar treatment. The lack of self-esteem that is so common in patients with AD feeds a lack of determination to seek better care, with some patients even reporting that they do not deserve what they consider to be 'preferential treatment'. Health systems tend to prioritize diseases where there are patients who 'shout the loudest'. AD patients need to be empowered to move out of their isolation and speak up about the true impact of AD on their lives.

In the context of the patient consultation, physicians feel strongly that there is a need for better two-way communication so that they can better assess the burden of disease – it is well known that patients habitually underscore the severity of their disease. A tool that assists in an objective evaluation would be of significant benefit. Providing patients with a pre-consultation check list has also proved successful in some countries. Part of a global campaign could include the roll-out of a suite of tools including decision-aids and checklists for AD patients.

5. Organization of services

In many countries, a lack of resource and capacity in dermatology means that patients face poor access – this can be due to a shortage of doctors in the specialty, and/or geographic issues, but it also can be a result of misdiagnosis in primary care or disorganized referral pathways in the health system.

There are many challenges to tackle lack of provision and the absence of linked services common to some countries. In addition, few patients have access to psychological services or basic support for living with AD, nor comprehensive and accurate information about their disease. Patient organizations in conjunction with dermatologist associations may be well positioned to advocate for improved AD training for primary care physicians and nurses as well as improving referral pathways. Socializing the value of psychological support for people living with AD or any chronic debilitating skin condition with health care providers would reap great benefit to patients.

6. Quality of care

In some countries, clinical guidelines for select dermatological diseases are well-established tools for improving organization of care and setting appropriate standards, such as in the USA, Canada, UK, and several European countries, yet these can carry little weight in many other countries. It is clear that even with the support of guidelines, securing better education for primary health professionals must be a priority for the global AD community. The need is particularly acute in primary care where guidance on risk stratification is essential for a prompt referral to the right specialist physician. Again, there are models at country level that can be drawn upon, e.g. CUBE C in the US, which is a multidisciplinary coalition of practitioners that has developed a holistic curriculum set for all practitioners, underpinned by shared decision making. In Japan, there is also a treatment algorithm that could be adapted. There are also a number of existing platforms at the country level, such as a central repository in the US that will aid sharing of best practices.

7. Access to innovation

There is a significant unmet need for effective safe long-term treatment options. It has been many years since there has been any innovative new treatment for AD and the community is excited about the new medicines that are in the pipeline. It cannot be assumed that patients will gain immediate access to these treatments however because of the requirements involved in national reimbursement mechanisms. Data that demonstrates the value of these therapies will be crucial and the community will need to monitor access challenges, and if necessary identify appropriate steps that can support timely access for patients.

Conclusion & Recommendations

This important round table discussion has revealed the breadth and depth of challenges facing the AD community. There is a shortfall in resources devoted by governments to this disease; AD does not feature in any health system's priorities. There are many consequences of this; inadequate training and awareness among healthcare professionals, and a lack of capacity to fully support patients who face debilitating physical and psychosocial problems. Many effective treatments currently available for AD have side effects or do not work at all; as a result the disease is often not well-managed. New treatments offer hope. Collaboration between all stakeholders in the AD community, alongside determined advocacy, and broad communication will be needed in order to ensure patients are able to achieve better outcomes in the future. IADPO believes adoption of the strategies presented here will help deliver this, alongside the key recommendations made at the round table meeting.

Potential collaboration between stakeholders in AD

- Create an alliance or formalized supported global community of national patient organizations in atopic dermatitis
- Develop a shared strategy to address current access challenges for patients with AD
- Advocate additional investment and research in new therapies to treat AD
- Compile new data to evidence the value of therapeutic interventions
- Include patients and caregivers in the development of care guidelines
- Develop a common language for AD that both patients and physicians understand
- Establish a global AD awareness day
- Drive more public awareness of the condition

Health system improvements that will support better care for patients with AD

- Identify obstacles in patient pathways at a national level and take steps to enable the introduction of fast-tracking of patients to specialist
- Formulate guidelines for the organization of dermatological services that are truly patient-centric in design

Clinical management of AD

- Improve training of health professionals in AD
- Develop tools for patients that will improve communication with doctors about their signs, symptoms, and burden of disease

Patient empowerment

- Establish a team of patient coaches and care navigators to enable patients to secure optimum care in their health systems
- Provide patients with resources to support optimal interaction with the specialist

If you have questions about this report, please contact:

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Appendix A: AD Round Table Meeting Participants



Julie Block	President & CEO, National Eczema Association	US
Chris Bundy, PhD, AFBPS	Psychologist, University of Cardiff	UK
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Amanda Cresswell- Melville	President & Executive Director, Eczema Society of Canada	Canada
Giuseppe de Carlo	Project & Finance Manager, European Federation of Allergy & Asthma Patient Organizations (EFA)	Europe
Peter Foley, MD	Assoc. Professor, of Dermatology, University of Melbourne	Australia
Marjolaine Hering	Member of the French Eczema Association	France
Christine Janus	International Alliance of Dermatology Patient Organizations (IADPO)	Global
Carlaraye Jones	Allergy UK	UK
Josef Pohunek	President, Psoriatic and Atopic Eczema Association	Czech Republic
Luis Puig Sanz, MD	Director, Dept. of Dermatology, Hospital de la Santa Creu i Sant Pau.	Spain
Nirohshah Suthakharan	Researcher, Institute of Health Care Research in Dermatology and Nursing, HECH	Germany
Cheryl Talent	President, Eczema Association of Australia	Australia
Alice Visintin	Coordinator Scientific Committees, National Association of Atopic Dermatitis (ANDeA)	Italy
Tonya Winders	CEO & President, Allergy & Asthma Network President, Global Allergy and Asthma Patient Platform	US

Appendix B: Backgrounder on Atopic Dermatitis (with citations)

Estimates suggest that up to 27% of the US population have some form of skin condition ^[30], and that 6.6% of the European Union population have skin problems, with significant differences between countries ^[31].

Atopic dermatitis (AD) is the most common form of eczema. It is currently an incurable, chronic immune-mediated systemic disease with a debilitating effect on 2-10% of adults worldwide ^[1]. Atopic dermatitis is more than ‘just a skin condition’. People living with atopic dermatitis feel its effects – both on their skin (often with a relentless itch, redness, swelling and lesions) and on their well-being (often linked to sleep deprivation, social isolation, symptoms of anxiety and depression, and an overall reduced quality of life). Patients with inadequately controlled atopic dermatitis face the devastating and unpredictable physical and psychological impact of the disease, every day.

Moderate-to-severe atopic dermatitis is characterized by painful lesions over large or sensitive parts of the body that can include skin dryness, cracking, redness, crusting and oozing ^[2]^[3]. Intense and persistent itching is one of the most debilitating symptoms, causing long-lasting, extreme pain, with more than 60% of moderate-to-severe patients reporting itch at least 12 hours a day ^[4]. There can be periods of time when the disease is characterized by ‘flares’ followed by periods when the skin improves or clears up entirely. AD is a chronic condition, often developing in infancy before the age of one. While AD can also develop in adulthood, up to 85% of adults with atopic dermatitis have lived with this chronic disease since childhood ^[14].

Disease exacerbations (more commonly known as flares) are common in adults with moderate-to-severe atopic dermatitis and typically require treatment or escalation of therapy ^[5]. Patients with severe atopic dermatitis report disease exacerbations up to 192 days per year, meaning that they spend over six months per year in a compromised state of health. Patients with moderate AD experience up to 113 days per year with AD exacerbations ^[5]. Currently, atopic dermatitis is managed by restoring the skin barrier, targeting symptoms, minimizing the number of disease exacerbations and reducing the degree and duration while minimizing treatment-related adverse effects. ^[6] ^[7]

Itch is one of the most burdensome symptoms for atopic dermatitis patients and can be very debilitating ^[4]. Severity and frequency of itch increases as the disease worsens. Adults with moderate and severe atopic dermatitis, compared to those with mild atopic dermatitis, report significantly more days per week with itchy skin (5.7 vs 2.7) ^[11]. Itching can lead to frequent scratching and result in secondary skin symptoms such as abrasions, bleeding, oozing, crusting, and leather-like skin thickening. Broken skin lesions, as a result of scratching, increase the risk of skin infections ^[2]. The relentless itch is also the main contributor to interrupted sleep with some patients stating that they have five to seven nights of disturbed sleep each week^[4].

As atopic dermatitis’ visible symptoms and lesions often appear on the hands and face, many adults with atopic dermatitis feel embarrassed, self-conscious, distressed, anxious and often avoid work and social activities ^[4] ^[5] ^[12]. Fifty per cent of atopic dermatitis patients report feelings of depression and/or anxiety ^[12], and 39% report feeling often or always embarrassed about their appearance ^[13].

Studies suggest that treatment failure rates within the current treatment landscape are high. Up to 78% of adults with moderate-to-severe disease do not experience significant improvements despite treatment ^[15] ^[16] ^[17] ^[18] ^[19].

Treatment

Current atopic dermatitis management strategies include restoring the skin barrier, targeting symptoms, minimizing the number of disease exacerbations and reducing their degree and duration while minimizing treatment-related adverse effects ^{[6] [7]}.

Topical corticosteroids (TCS) are recognized as the mainstay of atopic dermatitis treatment, but, like any medication, they come with the risk of side effects. For a subset of moderate-to-severe atopic dermatitis patients, TCS have been found to not provide adequate control of the disease or are not advisable ^{[8] [9]}. According to American Academy of Dermatology guidelines, oral immunosuppressive drugs (or systemic treatments) are recommended in AD care for the subset of patients for whom certain treatments (topical regimens and/or phototherapy) do not adequately control the disease. Nevertheless, these treatments are also linked with several short- and long-term adverse effects, safety risks, interactions and contraindications ^[10].

Currently, systemic therapy is used for some moderate and severe forms of atopic dermatitis inadequately controlled with topical treatment. Atopic dermatitis in adults can be challenging to treat due to the benefit/risk profiles of topical and systemic therapies ^{[10] [22] [23] [24] [25] [26]}. Emollients are used for the protection/restoration of the skin barrier and to help relieve skin dryness. If symptoms persist, patients typically undergo stepwise treatment reviews that 'add-in' topical corticosteroids (TCS) and topical calcineurin inhibitors (TCI), used for their anti-inflammatory properties ^{[8] [27]}. Topical emollients, TCS and TCI are the standards of care in AD ^[8]. Topical agents can effectively treat eczematous flares and, when used proactively, can prevent subsequent exacerbations. However, these may not provide adequate control to a subset of moderate-to-severe patients ^[9].

Cyclosporine is the only immunosuppressant drug with an approved indication for severe atopic dermatitis in some EU countries. Its approved use is limited to severe atopic dermatitis only and requires stringent safety monitoring and dose reduction as soon as a satisfactory response is achieved ^{[28] [29]}. The use of oral cyclosporine is limited because of its known toxicity including hypertension, impaired renal and hepatic function, and the potential for increased susceptibility to infections and cancer ^[28]. Off-label immunosuppressant use includes methotrexate, mycophenolate mofetil and azathioprine. The potential for toxicity, however, limits the long-term use of systemic therapies ^[8]. These immunosuppressant drugs provide broad-spectrum immunosuppression, and do not specifically target the underlying persistent inflammation in atopic dermatitis ^{[8] [10]}. Systemic corticosteroids are used as rescue therapy, for short periods, to quickly improve symptoms of acute atopic dermatitis ^{[8] [10]}.

Additional Facts

- Patients report that 10% of their working time is affected during an exacerbation ^[5].
- 57.5% of patients with atopic dermatitis report a decrease of sexual desire, with 36.5% of partners reporting that the appearance of the disease had an impact on their sex life ^[20].
- Up to 72% of patients with moderate to severe atopic dermatitis experience atopic comorbidities, including: asthma (approximately 40%), allergic rhinitis (38.5%-51%), allergic conjunctivitis (20%-24%), food allergy (34%), chronic rhinosinusitis (26%) and nasal polyps (13%) ^[4].

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