



EFA

European Federation of Allergy and Airways
Diseases Patients' Associations

Atopic

ECZEMA

ITCHING FOR LIFE

Quality of Life and
costs for people with
severe atopic eczema
in Europe

Itching

FOR

LIFE

July 2018

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ATOPICAL LIFE



Do you remember when you were a student or still at school? I do. Imagine yourself in an important exam and your whole body is itching as if every inch of your skin is covered with mosquito bites.

All you can think about is the itching. You try to control yourself and not to scratch. You just discreetly rub the itchiest area with the flat hand of your hand and rub ever so gently on top of your clothes. But you need to be careful, once you

start, the scratching can get out of hand. When it does, it's difficult to stop. You know that the damage has been done so you scratch until you bleed. Then, a fleeting moment of satisfaction comes when it's just pain, no itching.

After that, you start trying to build your skin barrier again. It will take months, with flare ups, improvements and setbacks and, in between, loads of cream, time and patience.

But let's get back to the exam. I managed to control myself, putting aside the itching, and I passed!

These are my experiences and I have mild to moderate atopic eczema. This report focuses on severe atopic eczema.

EFA wants to create understanding among people without this disease to help the Europeans who live atypical lives due to their severe atopic eczema, have a more normal life. They are itching for life.

We need your support.

Susanna Palkonen
EFA Director



FOREWORD



"I am not alone," was my first thought when I saw the results of EFA's survey on the impact of living with severe atopic eczema. Then came an emotional response - about my own suffering and that of all those others who suffer in silence.

I was only five days old when I developed severe atopic eczema. 54 years later, little has changed. The severity of my eczema comes and goes - a hallmark of this non-contagious skin disease. Because I have had it since I was a baby, I do not know what it is like living without eczema. It has always been there and so it has influenced who I am, how I function, my day to day routines, what clothes I wear and how I look at myself and at the world.

I have been a patient advocate for people living with atopic eczema for over twenty years, so I was delighted to be asked to participate in this landmark study on the impact of living with atopic eczema in Europe. Having personal experience, as well as some experience in research methodology, I was able to contribute substantially to this study. I also actively involved people living with atopic eczema in the development of the questions to be asked.

The results of the study are analysed in this report: they are incredibly significant. They echo many of my own experiences and the stories of the many people living with eczema with whom I have been in contact. For people living with eczema, the section about our specially developed questionnaire probably speaks the most truth about our lives because it was developed with the patients. It shows how we try to hide our eczema, how it influences intimacy, how hard it is living in a world where flawless skin is aspired to and how telling us not to scratch is useless: we do it anyway and at the same time we feel guilty about it. The saddest part, and I have experienced it myself, is that having severe eczema sometimes compromises our ability to face life.

For those with eczema who read this report please know you are not alone. That's what this study shows most powerfully. The feelings and emotions you are experiencing are shared with many people in the same circumstances in many countries. This does not change your symptoms, I know, but it might help to change the way you feel.

For those who do not have eczema or who are responsible for treating people with eczema, including health care professionals, insurers and policy makers: although eczema is a skin disease, its consequences are far more than skin-deep. It affects our hearts, our minds, our loves, our lives. We would like you to be aware of that, and we hope that now you are.

Bernd Arents

Atopic Eczema Patient Advisor for EFA from the Dutch Atopic Eczema Patients' Association
(Vereniging voor Mensen met Constitutioneel Eczeem - VMCE)



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WELCOME TO OUR REPORT



Although not always supported, quality of life for people with severe atopic eczema is well understood by dermatologists, who are our ambassadors. Beyond them, there is little awareness about atopic eczema. Even those who live with patients with atopic eczema do not understand the full impact it has on people, except perhaps the families who share the pain of sleepless nights because of an unhappy, suffering child.

As allergy, asthma and COPD patients' advocates, at EFA our mission is to voice the needs and rights of patients, but we need accurate data to shed light onto the real lives of the patients we represent. For this reason, EFA brings you this report, to give a voice to the millions of adults who are silently and patiently dealing atopic eczema.

The report Itching for life - Quality of Life and Costs for People with Severe Atopic Eczema in Europe is the result of the largest survey ever done on quality of life in severe atopic eczema in Europe. We asked patients from the North, in Denmark, Sweden and the UK, the South in Italy and Spain, the East in the Czech Republic and the Centre and West in Germany, France and The Netherlands to provide a pan-European picture of living with and bearing the costs of the disease.

This report will help us create awareness and understanding of atopic eczema and the real impact of its most severe form. The report is addressed to:

- Patients, to send the message that you are not alone and something is being done to bring attention to the impact this condition has on your lives
- National and international healthcare professionals and researchers (dermatologists, allergists, primary care physicians, nurses, and pharmacists), so that the burden patients bear is shared, eased and removed
- EFA member associations, our partners, and other skin associations, as a tool in their work to improve the lives of people with atopic eczema and
- EU policy makers, to encapsulate the burden experienced by European patients and consider and recommend solutions.

I would like to thank Bernd Arents from the Dutch Atopic Eczema Association, our ultimate expert, creative and committed patient adviser for the survey, as well as Professor Johannes Ring as medical advisor, for steering the scientific approach with his wisdom. I thank our sustainable funding partners Regeneron and Sanofi Genzyme who believed in us through all the challenges, and supported this project with unrestricted grants. Lastly, I thank our project team, Antje, Giuseppe, Isabel and Sofia and IMAS International, for their persistence in conducting the survey and for getting the job done.

Finally, this report belongs to the 1,189 patients who helped us with this survey. You made a difference and now it's up to us to steer the results to bring about change, working together.

Mikaela Odemyr
EFA President





**ATOPIIC ECZEMA
AND EUROPE**

ATOPIC ECZEMA AND EUROPE

We live through our skin

Our surface is made of skin, between 1 and 2 square meters of it. As the largest organ of the human body, the skin not only presents us to the outside world but also protects us from the outside. Every bit of our skin is alive and ready, to help regulate our body temperature, to enable us to experience the environment we live in, whether it is the sensations of touch, heat, cold ... or love.

Skin has many layers. What we see on the outside is just scratching the surface. Diseases affecting our skin have greater effects than the damaged surface we see. Atopic eczema is not only an aesthetic problem, it comes from under the skin. While the actual causes remain unknown, science has advanced to understand the underlying mechanisms, what happens in the layers of our skin and the human immune system.

When atopic eczema becomes itchier, patients scratch more. Scratching the eczema, leading to more itch, and setting the itch-scratch-itch pattern. This vicious circle causes a high state of anxiety and stress, resulting in an additional burden for patients .

(Hong J., Buddenkotte J., Berger T. G. & Steinhoff M., 2011)

Atopic eczema in Europe

Atopic eczema is defined as an immune-inflammatory, pruritic, chronic or chronically relapsing skin disease often occurring in families with other atopic diseases (asthma and/ or allergic rhinoconjunctivitis). It is one of the most common chronic inflammatory skin diseases and affects up to 20% of children and 2–8% of adults in most countries of the world, and 3.5-4.4% of Europeans¹. For almost 10% of patients with atopic eczema the condition is severe^{2,3}. Their skin becomes itchy and, during flare ups, it can become infected from scratching, which can result in oozing of fluid, the formation of yellow crusts or spots, swollen and sore skin and resulting fever.

Atopic eczema has for too long been dismissed as a superficial, trivial skin disease. The chronic and relapsing nature of atopic eczema impacts hugely on patients' wellbeing and quality of life, especially for those in whom it is severe.

In common language, patients and healthcare professionals in Europe refer to the disease as eczema. In clinical language, atopic eczema is called differently in different languages known as:

CZ - Atopický Ekzém

DE - Neurodermitis

DK - Børneeksem

ES - Dermatitis Atópica

FR - Eczéma Atopique

IT - Dermatite Atopica

NL - Constitutioneel Eczeem

SE - Atopiskt Eksem

UK - Atopic Eczema

Atopic eczema = Atopic Dermatitis = Eczema = Endogenous Eczema = Neurodermatitis

In this report we use the term Atopic Eczema

¹ Barbarot S., et al, 2018.

² Wollenberg, A., et al, 2018.

³ Atopic Eczema is generally considered as severe when it gets a SCORAD (SCORing Atopic Dermatitis, developed by the European Task Force on Atopic Dermatitis in 1993) above 50 or an EASI (Eczema Area and Severity Index) score 3 (Oakley A., 2015). These two indexes differentiate mild, moderate and severe eczema assessing the extent and severity of eczema. On the one hand, besides evaluating the disease extent and intensity, SCORAD assesses subjective symptoms such as itch and sleeplessness. On the other hand, EASI does not include a grade for dryness or scaling, but only include inflamed areas.

About the *Atopical lives* survey

The 1,189 participants in this study were adults with severe atopic eczema (over 18 years old), 56% women and 44% men. The average age was 42.

Most of the patients had a light or intermediate skin⁴. Dark skin types were less represented and were mainly the Mediterranean skin types from Spain and Italy. Most of the patients live in medium-sized towns (39%), one third in metropolitan areas, and one quarter in rural areas and villages.

The survey was conducted according to Quality of Life (QoL) and economic impact survey methods. All patients in our survey had received a diagnosis of severe atopic eczema.

To measure quality of life and cost in a way that can be compared across countries, we used existing scientifically validated instruments. We checked:⁵

- the current status of atopic eczema/dermatitis, how severe it/the symptoms were at the moment of the interview⁶;
- the psychological burden of the disease⁷
- the quality of life related to living with atopic eczema⁸
- emotional consequences⁹
- cost of treatment and prevention

We also asked about care.

The emotional consequences atopic eczema has on patients were measured through a new validated tool developed by EFA. The Atopic Eczema Score of Emotional Consequences (AESEC[©]) takes into consideration items listed in other Quality of Life studies together with aspects frequently discussed by people with atopic eczema in social media. The items were intentionally reworded into positive and negative statements and were then checked by specialists in psychology, research and language. A questionnaire containing 37 items was pre-tested online in 5 EU-countries (n=100) to inform our selection of the most sensitive and reliable statements. The resulting validated AESEC[©] contains 28 items, chosen according to methodological reliability.

1 in 10 atopic eczema patients suffers from a severe eczema form.

⁴ Light brown skin type, light to dark brown/blond hair bright or brown eyes, hardly freckles, slow/progressive tanning ability, low sun burn risk.

⁵ Interviews were done between October 2017 and February 2018. Atopic eczema, while chronic, is also very variable, also through seasons and weather conditions.

⁶ The Patient Oriented Eczema Measure (POEM) refers to the disease severity at the time of interview and the week before the interview.

⁷ The Hospital and Anxiety Depression Scale (HADS).

⁸ The Dermatology Quality of Life Index (DLQI).

⁹ Atopic Eczema Score of Emotional Consequences (AESEC) developed during this project by EFA, see box.

Our study included 1,189 people with severe atopic eczema. They were either on the so-called systemic treatment and/or phototherapy, or could be because of the severity of their atopic eczema. Given that there is no proper definition for severe atopic eczema, patients in this study were defined as severe by their need for certain treatment.

The 1,189 patients were mainly recruited through physicians (84%) and the rest (16%) through patients groups, recommendations from patient leaders, patient support groups in social media and other. In the Czech Republic, Denmark, Sweden and the Netherlands it was not possible to recruit all the patients via physicians due to national regulations. Patients who were not recruited through physicians, were screened twice and asked if they ever received a diagnosis by a physician confirming the severe form of atopic eczema as diagnosis. Those who did not reply with a clear 'yes' to this question were not included in the survey.

The patients from 9 different European Union countries (Czech Republic = 52, Denmark = 50, France = 180, Germany = 180, Italy = 180, the Netherlands = 150, Spain = 180, Sweden = 37, and United Kingdom = 180) were interviewed via telephone.

In Sweden it was not possible to reach the target number of patients (50). However, due to the large size of the sample, this does not affect the validity and the quality of the results.



2

MANAGEMENT OF ATOPIC ECZEMA

MESSAGES *from* PATIENTS IN THE SURVEY

«The skin is the largest organ. It is very difficult, complicated and obstructive if you suffer from it every day. The whole day your skin feels itchy and painful. **You have to do your very best to function normally.**»

Atopic eczema patient
from the Netherlands

«I would like to say to people that it is possible to overcome the disease. **It is possible to live with this disease. We can do it!**»

Atopic eczema
patient from Italy

« I think **we still have to suffer** a very long time with the disease. If there would be more research, there would be better methods to heal it.»

Atopic eczema patient from Spain

«There are many people who are **suffering silently**, the general public don't know what it means to have eczema.»

Atopic eczema
patient from Sweden

«If you deal critically with yourself and the illness then **you can hope for betterment.**»

Atopic eczema patient
from the United Kingdom

«You can improve the quality of life with a good treatment, eczema is unfortunately not curable, but you can feel very well having a well-treating doctor and you can **look optimistically into the future.**»

Atopic eczema patient from Germany

«The medical world is sometimes being so difficult, they do not cooperate. I really had to urge the dermatologist to look further. He did not want to. Eventually I went to an allergologist and it turned out to become better with a dietary adjustment. It's important to **work together** and to look beyond.»

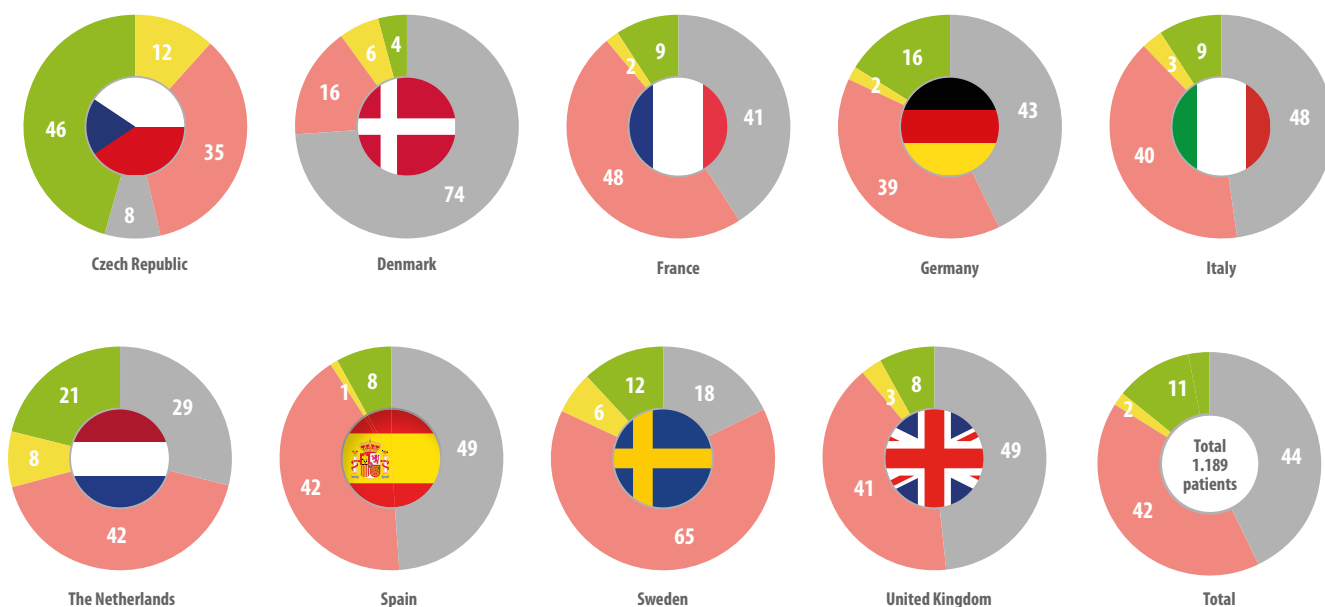
Atopic eczema patient from the Netherlands

MANAGEMENT OF ATOPIC ECZEMA

Diagnosis of atopic eczema depends on the country

The initial diagnosis of atopic eczema is mostly done by general practitioners, the ‘family’ doctor (43%), and dermatologists (41%). Paediatricians diagnose 11%, allergologists 2% and the other 3% of patients are diagnosed by other healthcare professionals. In our survey, patients coming from France, Germany, Italy, Spain, and the United Kingdom, were mainly diagnosed with atopic eczema for the first time by general practitioners (GPs) (43%) and dermatologists (41%). In Denmark, 74% of the atopic eczema patients surveyed were first diagnosed by their GP. In the Netherlands, Sweden and Czech Republic, GPs were the first to diagnose 29%, 18% and 12% of the respondents. In Czech Republic 46% and the Netherlands 21% patients were more likely to be diagnosed by paediatricians. Finally, in Sweden dermatologists were the first, diagnosing more than half of the patients.

Table 1. Healthcare professionals diagnosing my atopic eczema



Values in % of patients getting first diagnosis from: ■ General Physician ■ Dermatologist ■ Allergologist ■ Paediatrician

«We should be treated better, starting from the diagnosis, so that we can receive a better and faster treatment. Currently it takes too long before you see improvements.»

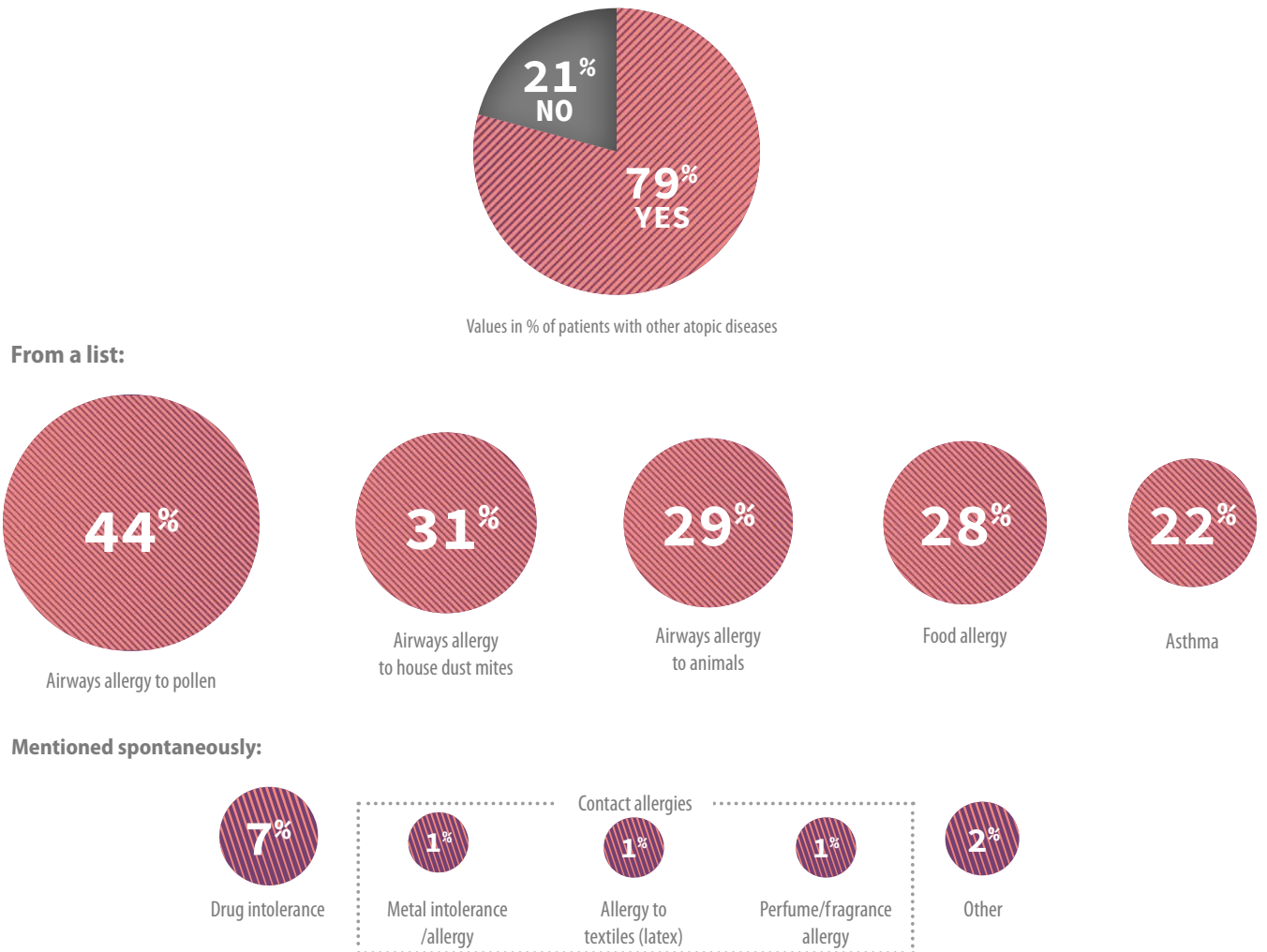
Atopic eczema patient from Italy

«Everybody can be affected by atopic eczema. We need more clarification by doctors and above all they should not simply prescribe a bit of ointment.»

Atopic eczema patient from Spain

A majority of patients (79%), have other atopic diseases such as asthma and allergies to pollen, house dust mites, animals, food ingredients and contact allergies or drug intolerance which makes their life and treatment more complicated. Additionally, atopic eczema patients live with other chronic diseases, including metabolic diseases, airways diseases, high blood pressure and cardiac diseases, as well as other skin diseases, making the case for the need for correct diagnosis and patient centred multi-disciplinary care.

Figure 1. Other atopic diseases that I have



For 4 in 5 severe atopic eczema patients, their disease burden is multiplied by other allergies and asthma.

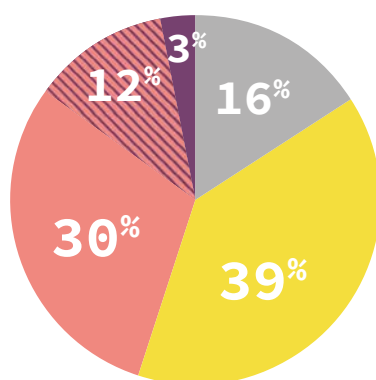
«There should be more focus on the healthcare team, like dermatology, immunology and allergy.»
Atopic eczema patient from Sweden

«Talking to the doctors sometimes gives you the feeling that you're not taken seriously. It is not a threatening disease, but we suffer a lot mentally.»
Atopic eczema patient from France

Severe atopic eczema does not give a break

We asked the patients in our survey how severe their symptoms were in the week before the interview¹⁰. Despite current treatment, and the fact that the majority of patients in our survey are receiving care because they were recruited through doctors, up to nearly 1 in 2 patients (45%) still suffered from serious eczema symptoms. This was even higher among participants from Germany and the Netherlands. There is no effective escape from severe eczema.

Figure 2. The severity of my symptoms in the previous week

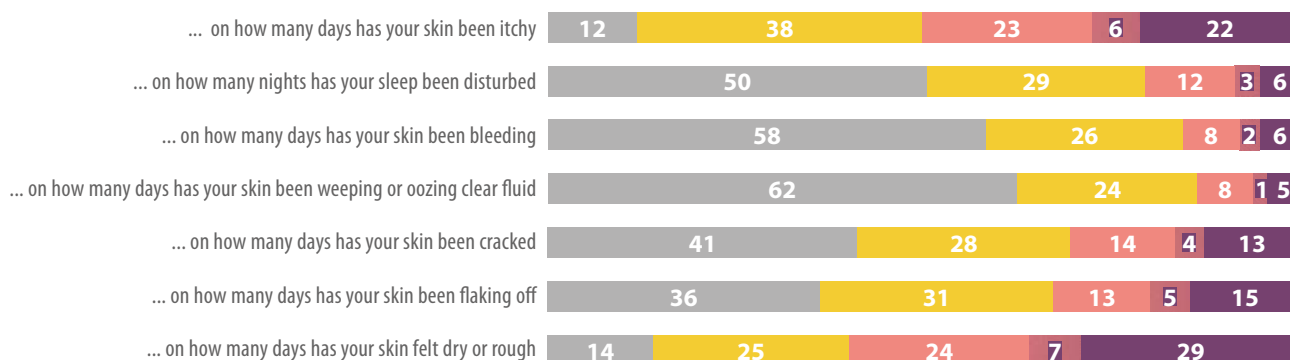


Values in % of patients with symptoms: ■ clear/almost clear ■ mild ■ moderate ■ severe ■ very severe

Patients are living with recurrent symptoms almost every day. For example, during the week before the interview, 36% of the patients noted their skin was dry or rough, 28% had an itchy skin, 20% felt that their skin was flaking and 17% had cracked skin.

Atopic eczema impacts on life every single day, not only during eczema flare-ups. Not having a skin that protects us has a huge impact on our general health condition. Patients who had clear skin or mild atopic eczema in the week before their interview for our survey, generally also reported having a good or very good health status. Patients who were suffering from moderate or severe atopic eczema symptoms in the week before the interview mostly described having a bad or very bad health condition. When moderate or severe symptoms exist, general health is poor.

Figure 3. The condition of my skin in the previous week



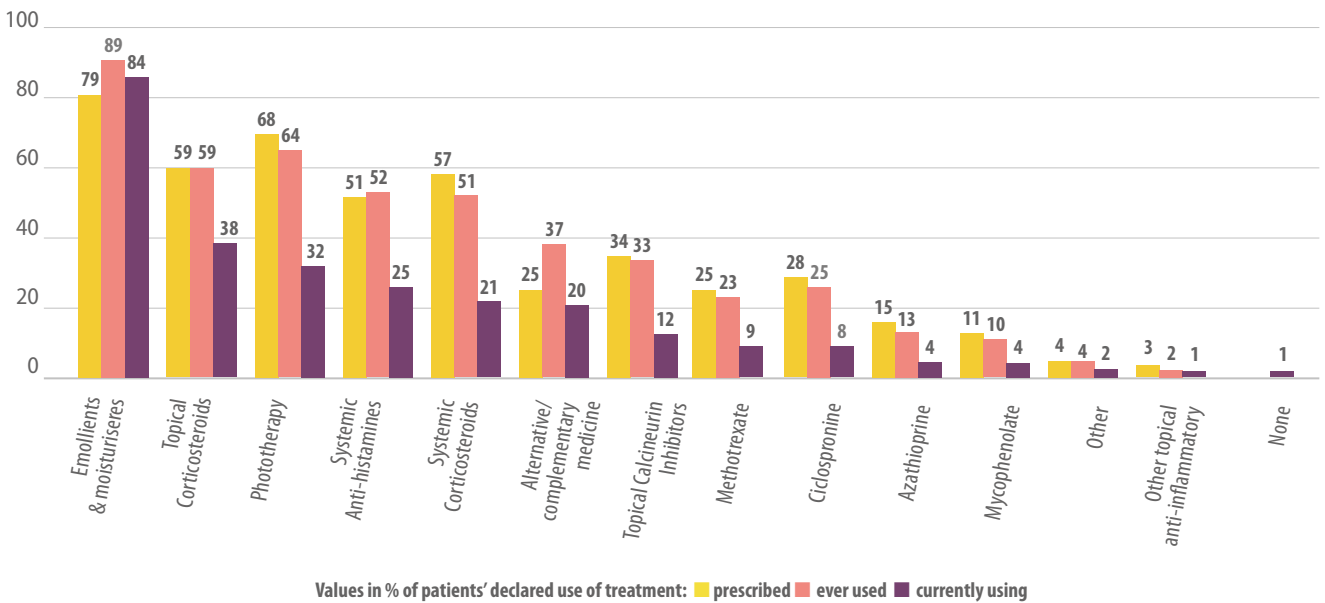
Values in % of patients with skin symptoms: ■ no days ■ 1-2 days ■ 3-4 days ■ 5-6 days ■ every day

¹⁰ Measured with the validated Patient Oriented Eczema Measure (POEM), a validated, patient-derived assessment measure for monitoring atopic eczema severity in the past week. By being a measurement in a specific point in time, POEM score can vary according to patients' response to treatment and other external factors. This means that a patients with severe atopic eczema can have its disease under control when he/she took the survey and therefore suffer from less serious symptoms in that week.

Treatment options need to be improved

The most prescribed treatments currently used in Europe are emollients/moisturisers and topical corticosteroids. Severe atopic eczema patients are also prescribed anti-histamines, oral corticosteroids, systemic immunomodulatory therapy and phototherapy, but they do not necessarily use all of these treatments as prescribed: patients are concerned about the side effects (66%) or have a negative perception of treatments. Also, the treatment is not always reimbursed or affordable and they may also feel there is no need to use it. People with atopic eczema have to self-manage and juggle their changing skin condition and they will make their own decisions on a daily basis, depending on many factors.

Table 2. My prescribed, ever used and current treatment in Europe



«The treatment of atopic dermatitis requires a multitude of individualized coordinated measures on the patient. The greatest challenge is the treatment for the tormenting itching.»

Atopic eczema patient from the United Kingdom

Despite care, 1 in 2 severe atopic eczema patients live with their symptoms every day, in recurring cycles.

«Doctors should be looking for alternatives beyond corticosteroids because they only solve the symptoms.»

Atopic eczema patient from Czech Republic

59% of the patients were using systemic treatments¹¹ or phototherapy, which is often prescribed to patients with severe atopic eczema, and they were generally satisfied with them. An exception was cyclosporine, because of its impact or side effects.

Table 3. My prescribed, ever used and current treatment by country



Values in % of patients' declared use of treatment : ■ prescribed ■ ever used ■ currently using

«The investigation must be broader. Not only conventional medicine should be contemplated or considered.»

Atopic eczema patient from Spain

¹¹ Systemic treatments are medications taken as tablets or injections, and go through the blood system, dampening down the immune system to reach and treat eczema all over the body (Wright, A.).

In Denmark, phototherapy is used much less than in the other countries in our survey. Danish respondents were highly prescribed and widely used oral Corticosteroids, followed by ciclosporine and azathioprine. Within the survey, in Denmark, but especially in Sweden, methotrexate is used more than in the other countries.

Surprisingly, patients are overall satisfied with the different treatments. But participants with moderate to severe eczema symptoms at the time of the interview are much less satisfied with their treatment.

Participants reported being satisfied or very satisfied with the treatment (79%) because of the good results it provides to them. They feel happy with their treatment if it has a positive impact on their quality of life, if it improves their skin condition and appearance and if they do not experience side effects. Among the 79% of satisfied patients, only 15% of them are very satisfied with the treatment in general.

The disparities between use of treatments as prescribed, severity and satisfaction with treatments and the severe impact on quality of life reported in this survey need a closer look. Patients should be able to expect less symptoms and better quality of life and our findings is consistent with many other chronic diseases: patients adjust and do not expect more from their treatment.

«I would like people to believe in the need for research on atopic eczema. My child has it - and I can see it worrying her more than it does to me.»

Atopic eczema patient from Denmark

2 in 3 patients with severe atopic eczema are concerned about side-effects.

Atopic eczema is a tedious disease. You have to try several therapy options until you have found the right one for yourself. Many medications have high numbers of side effects, the weight gain is particularly annoying.

Atopic eczema patient from Germany

«Living with eczema can be hell. There is so little news in medicine, no development of medication. Is there no research done anymore? It seems like eczema patients are not important enough. I also used a lot of medicines. Now it's going very well.»

Atopic eczema patient from the Netherlands



IMPACT ON LIFE

MESSAGES *from* PATIENTS IN THE SURVEY

«This disease must be taken more seriously. In cancer patients, one is dismayed about it, but in our illness, we react as if it were our fault.»

Atopic eczema patient from Spain

«It's a disease that you can never get rid off. Learning to live with it requires discipline and support.»

Atopic eczema patient from Denmark

«Atopic eczema is not dirty. It's just bad luck, people should not look at you like that. I cannot help it, it's not my fault.»

Patient from the Netherlands

«Sometimes it is hard doing the things other people can do, but I can feel that I can handle my eczema.»

Atopic eczema patient from United Kingdom

«It has a great impact on your life. But you also adapt your lifestyle in a natural way. You know you have limited career opportunities. You won't have a managerial function because that is stressful. I do not care about what people think of my skin.»

Atopic eczema patient from the Netherlands

«The eczema is bad, but the itching is much, much worse. You cannot see it, but it has a very negative effect on concentration and the daily life, like influence on the sleep quality. Being pitied is also unnecessary.»

Atopic eczema patient from Germany

IMPACT ON LIFE

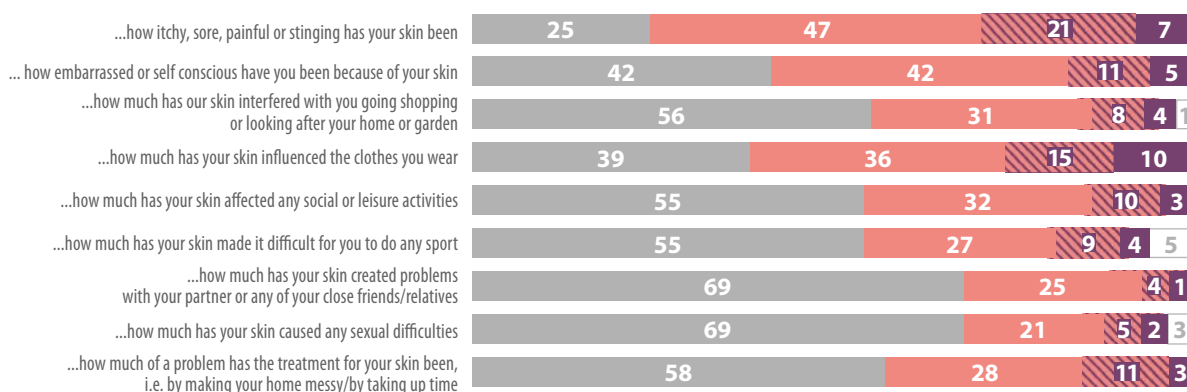
Atopic eczema impacts patients' lives beyond the skin

Atopic eczema is a disease that affects people's skin and so its consequences can be very visible. However, the impact of the disease is much larger than what you can see, as it considerably impacts on quality of life.

The look of their skin affects patients. Their skin makes them feel embarrassed (58%), influencing their daily lives, such as the clothes they choose to wear (61%)¹².

However, whilst 55% do not let their condition restrict their social life and leisure activities there are those (45%) for whom there was an impact on their relationships, sexual life and hobbies, such as sports, in the week before the interview. While it may be true that atopic eczema does not often prevent patients from working or studying, 38% of the people interviewed declared feeling impaired at work because of their skin.

Figure 4. My quality of life with atopic eczema



Values in % of patients' quality of life: ■ not at all ■ a little ■ a lot ■ very much □ not relevant

«This disease is a hard time, especially in summer, everything hurts, itches and you scratch until you bleed. Without the support of the family and doctors, it would be very difficult to deal with atopic eczema.»

Severe atopic eczema patient from Germany

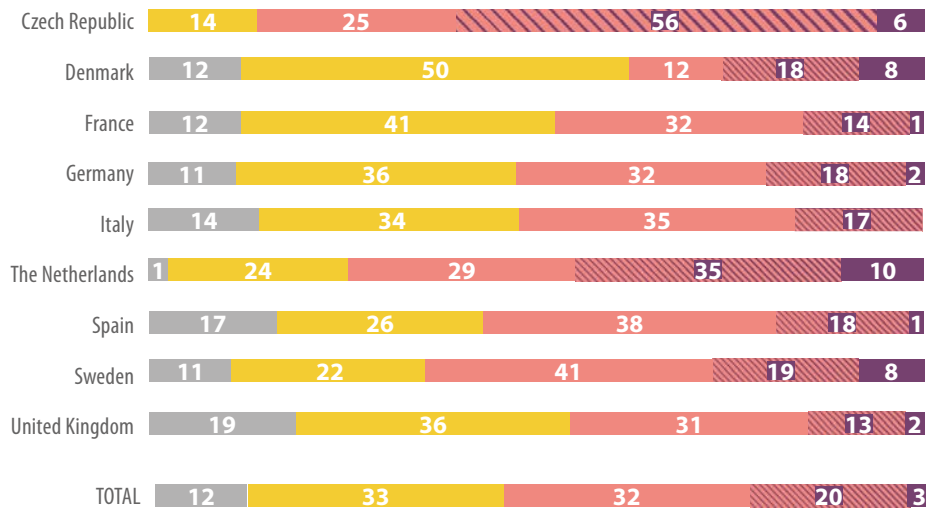
«Atopic eczema has a bigger impact than what you can see, like the lack of sleep, or the ointments. Applying ointments affects what you can do, you are slippery and smelly.»

Severe atopic eczema patient from the Netherlands

¹² Measured by the validated Dermatology Quality of Life Index (DLQI).

Patients with few or mild symptoms at the time of their interview experienced less effect on their quality of life (only 9% of them had moderate, large or very large effect) than those with currently moderate to (very) severe symptoms (90% of them had moderate, large or very large effect). On average however, whether having severe symptoms or not, the impact on quality of life is moderate to large for at least half of the patients. The Czech and the Dutch patients who answered the survey report higher impact on their quality of life compared with other countries, where patients consider the impact as moderate.

Figure 5. The impact atopic eczema has on my life



Values in % of the impact of atopic eczema on patients: ■ no effect ■ small effect ■ moderate effect ■ very large effect ■ extremely large effect

The more severe the atopic eczema symptoms are, the heavier the impact is on the quality of life of the patients.

«Atopic eczema is a very demanding disease in both psychological and financial terms. Sometimes I am not able to hold anything with my hands, I need help but day care is not possible.»

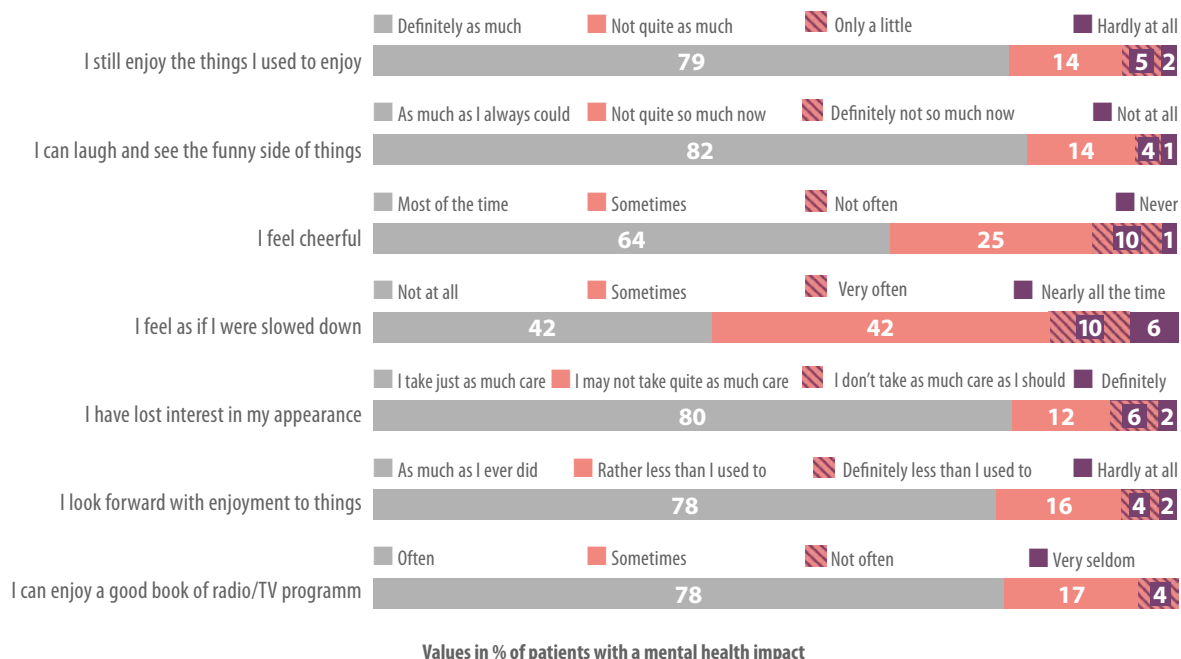
Severe atopic eczema patient from Czech Republic

Severe atopic eczema symptoms can lead to depression

Overall, 1 in 10 patients showed a depressive mood.¹³ Yet 30% of those with severe symptoms at the time of the interview suffer high psychological strain and depressive mood. On top of the disease and its symptoms, atopic eczema patients carry a substantial psychological burden that worsens during flare-ups.

Atopic eczema affects the energy level of the patients, making them feel ‘slowed down’. Many don’t feel cheerful in their life and lose interest in taking care of their appearance.

Figure 6. The impact atopic eczema has on my mental health



The more severe the atopic eczema symptoms, the higher the risk for depression.

«I wouldn't wish this disease on my worst enemy, atopic eczema... it's disgusting. One's life becomes easily depressing.»

Severe atopic eczema patient from Denmark

«Pay more attention to us, we are also suffering even when we are not supposed to die. The mental health problems are underestimated.»

Atopic eczema patient from the United Kingdom

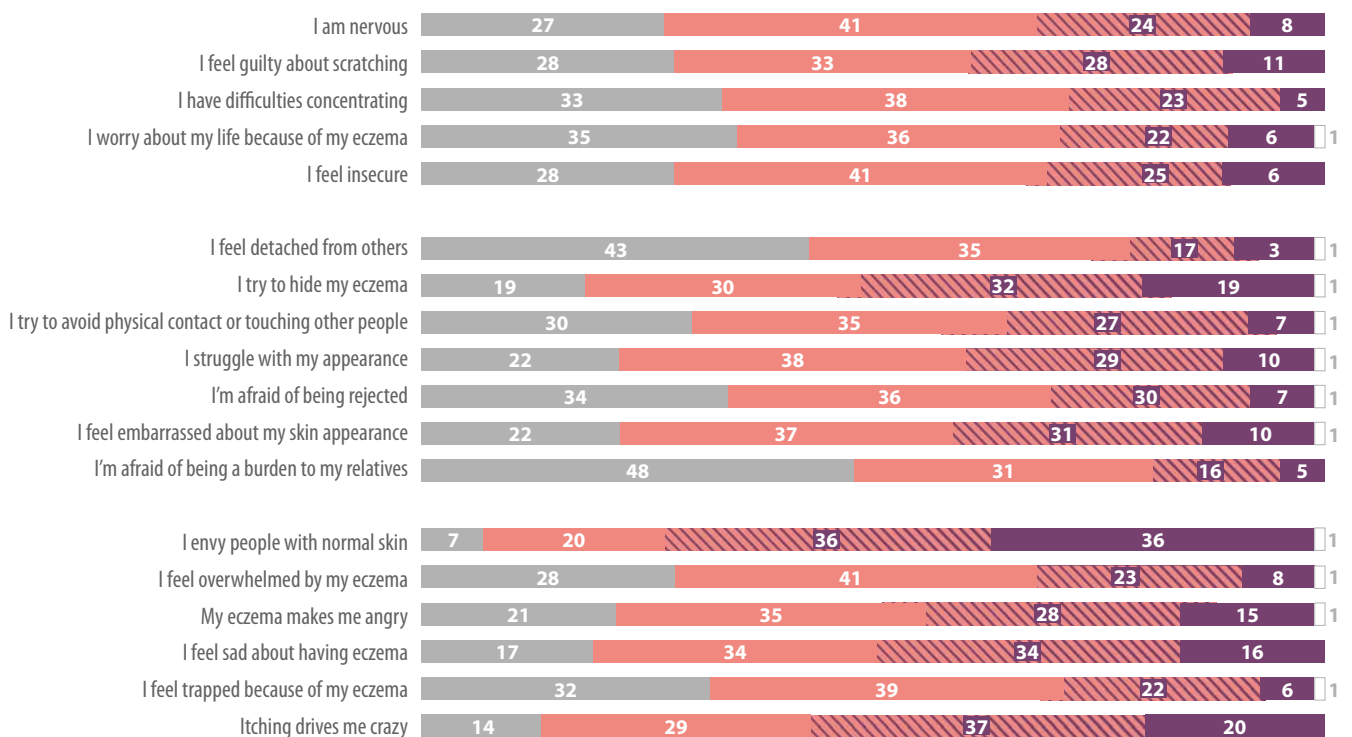
¹³ Measured by the validated Hospital and Anxiety Depression Score (HADS).

Atopic eczema controls one's emotions

Up to 1 in 4 patients feel that they cannot cope well with their eczema and feel that they are not able to keep it under control.¹⁴ Worryingly, they do not have an optimistic view about their life with eczema (23%). Patients live through many difficulties due to an itch they fail to control and which can last for a long time. For the majority (57%), itching is driving them crazy. Half of the participants (50%) also said that their atopic eczema makes them feel sad. 72% feel envy towards people with healthy skin.

Patients would like to have a normal skin and are ashamed of theirs. They try to hide their eczema (51%) and feel embarrassed or struggle with their appearance (40%). 1 in 3 even try to avoid physical contact with other people and 39% of the participants consider their intimate relationships problematic. The impact on life quality is especially high for Czech and Dutch patients who answered our survey.

Figure 7. The emotional consequences of atopic eczema - Negative items



Values in % of patients with emotional consequences: ■ does not apply at all ■ rather not ■ somewhat applies ■ applies fully □ no answer

«Many people feel don't feel comfortable when I'm around, this is not nice, nor justified. People don't have to be scared, I'm not contagious.»

Severe atopic eczema patient from Italy

«All people always emphasize how tolerant they are, but if they are close to me, for example sitting in the same restaurant, they try to look the other way or even sit in another place.»

Atopic eczema patient from Spain

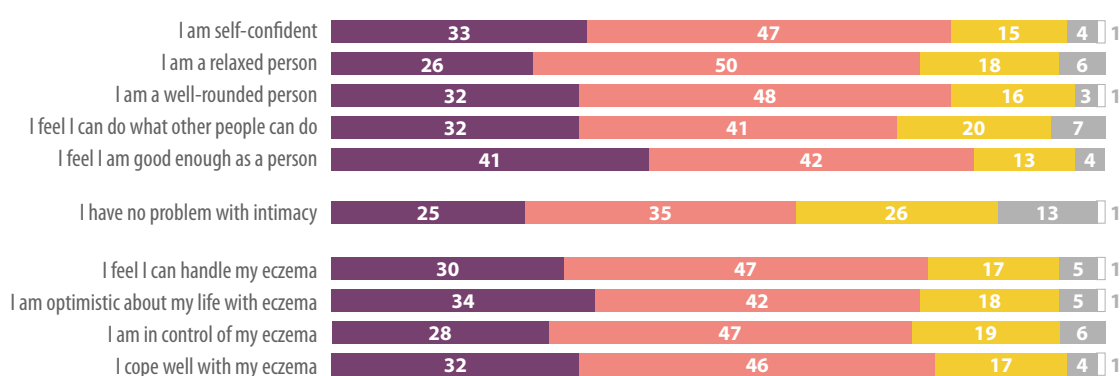
¹⁴ Measured by the validated Atopic Eczema Score of Emotional Consequences (AESEC).

Atopic eczema is tougher on people than we thought

Emotions are often negative towards oneself: 39% of patients feel guilty about scratching, 32% get nervous, 31% feel insecure and 28% have difficulties in concentrating and are worried about their life. Patients also feel like they do not have the same opportunities as other people: 1 in 4 cannot do things in life that other people can do.

In general, the impact of severe atopic eczema on their life is important or very important for 30% of the patients. The more severe the symptoms are, the more severe the impact on their life is. Over 60% of the patients with severe or very severe symptoms experience the highest impact (large to very large). They also feel less optimistic, less balanced, have increased problems with intimacy and feel less in control of their eczema.

Figure 8. The emotional consequences of atopic eczema - Positive items

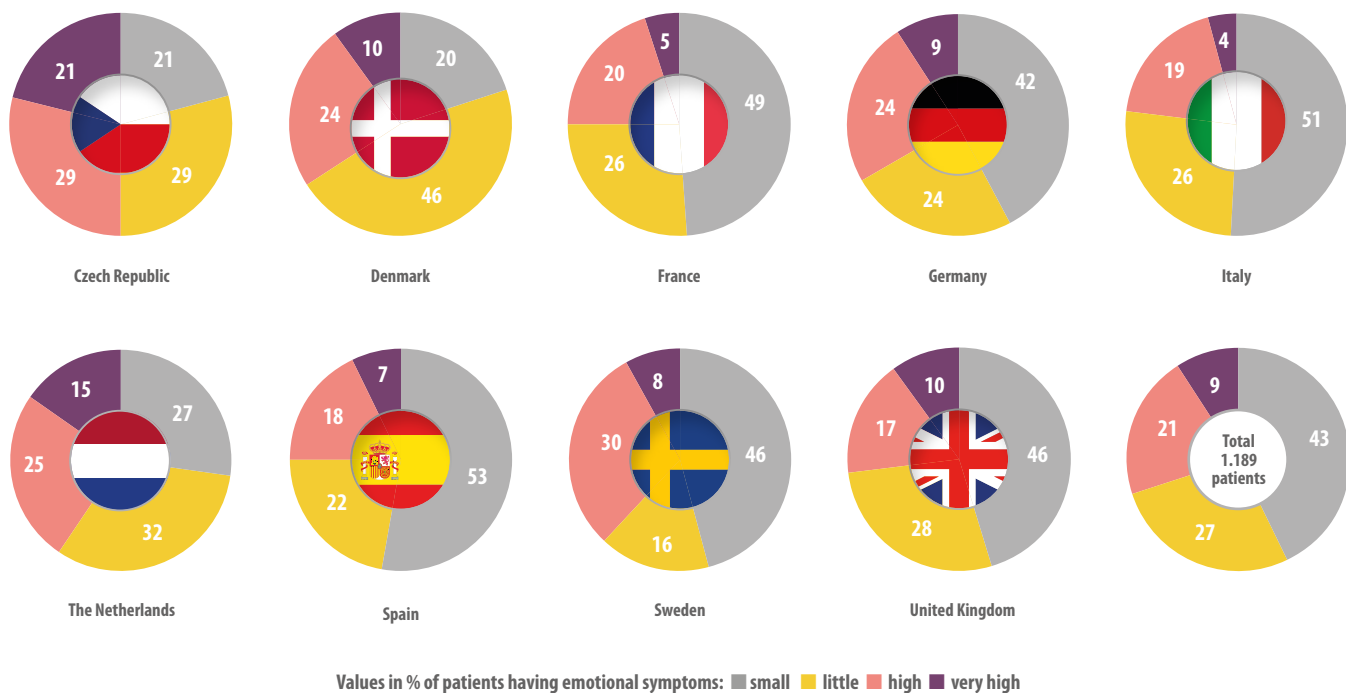


Values in % of patients with emotional consequences: ■ applies fully ■ somewhat applies ■ rather not ■ does not apply at all □ no answer

«The one who has the disease doesn't live anymore, avoids to go out or to meet people, the psychological state of mind is really impacted and it can get dangerous.»

Atopic eczema patient from France

Figure 9. The impact atopic eczema has on my emotions



23% of atopic eczema patients do not have an optimistic view on their life with eczema and 57% say itching is driving them crazy.

«Atopic eczema takes a lot of energy. I think I cannot take it anymore.»

Severe atopic eczema patient from Sweden



COST AND SICK LEAVE

MESSAGES *from* PATIENTS IN THE SURVEY

«I would like if skin care products were paid by the health insurance, the increased need for them is already a burden, I of course have an increased need for care. More causes-treatments should be explored on the patient as such.»

Severe atopic eczema patient from Germany

«We need more financial support. Everything is so expensive!.»

Severe atopic eczema patient from Italy

«In acute conditions, it puts a lot of strain on people, both mentally and physically, and it also puts a strain on finances, healthy living is expensive, and eczema limits many things you can eat, and many things are expensive and you have to be able to afford it!.»

Severe atopic eczema patient from Germany

«People spend more money on cleaning products, special gloves and make-up because they are more expensive than ordinary products. Special shampoo is very expensive, for example!.»

Severe atopic eczema patient from the Netherlands

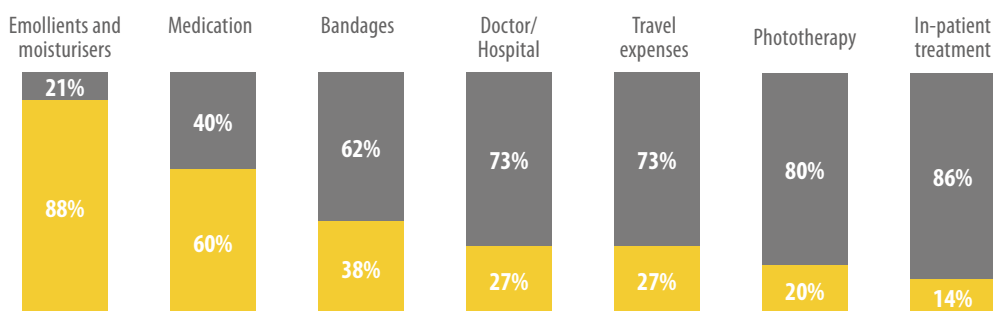
COST AND SICK LEAVE

Out of pocket expenses for care are standard

Extra healthcare spending is another setback for people living with atopic eczema because treatments and care are not always reimbursed. Only 5% of the respondents do not have out of pocket expenses related to the condition. Almost all patients pay on average €927.12 per year for their atopic eczema treatment. In particular, emollients and moisturisers cost most per month (€27.61 on average), followed by €17.74 monthly for medication.

In our survey, Dutch patients spent much less money every month (€57) compared with the average (€77.26). Danish and Swedish patients pay more every month, in general, than patients from other countries.

Table 4. My monthly out of pocket expenses for health care



Values in % of patients: ■ Patients with out of pocket expenses ■ Patients without out of pocket expenses

Patients spend 77 euros on average every month for their care.

«Living with atopic eczema is a hard life, the treatment must be good, you have to check up every month and pay a lot of pounds for medication and other things.»

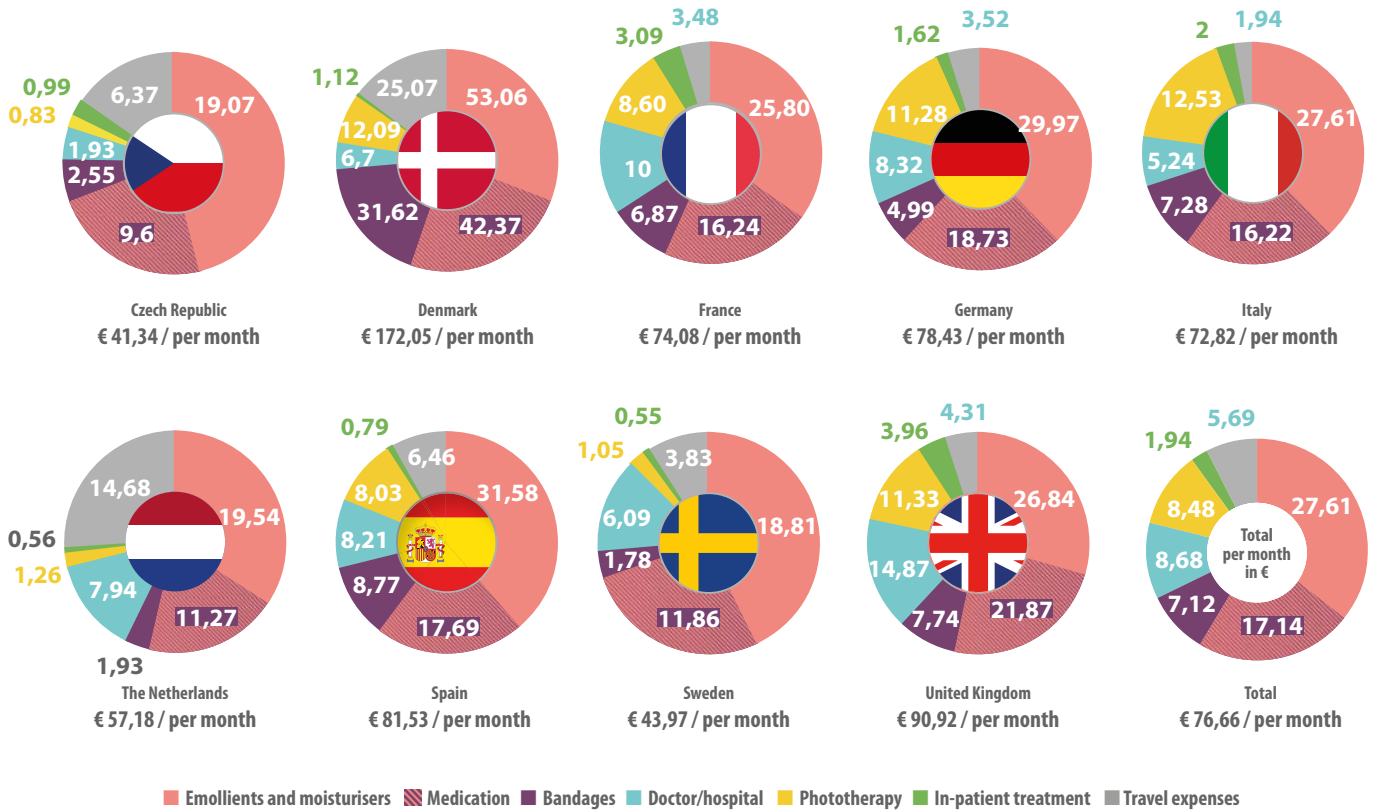
Severe atopic eczema patient from the United Kingdom

«A disease like atopic eczema is very costly. Financial support from the health insurance would be good. Especially regarding light therapy, if you have acute relapses, you have to pay for the therapy yourself mostly.»

Atopic eczema patient from Germany

Unlike the effects on the quality of life of patients, healthcare expenses are not much influenced by the severity of atopic eczema. Patients suffering from clear or mild atopic eczema incur very high extra costs as well (only a 9% variance). The likely explanation is that most of the out of pocket costs go to cover emollients and moisturisers and treatments used (in great quantities) by almost all respondents.

Table 5. My monthly out of pocket expenses for health care per country



«Making atopic eczema liveable costs a lot of money. There are many extra costs in order to live at a normal level. This is almost not achievable. Sports, vacation, eating, living in the house, work - everything is affected by the atopic eczema.»

Patient from the Netherlands

«I clearly want more financial support. All personal care products and quality clothing are very expensive.»

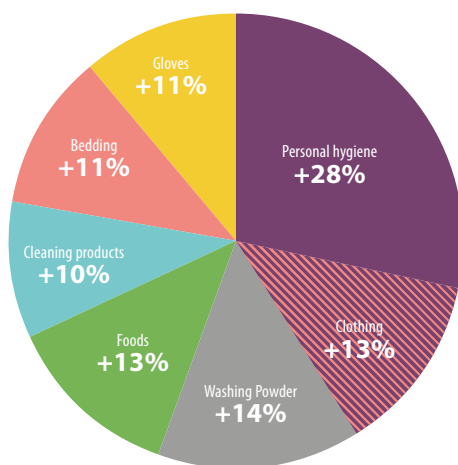
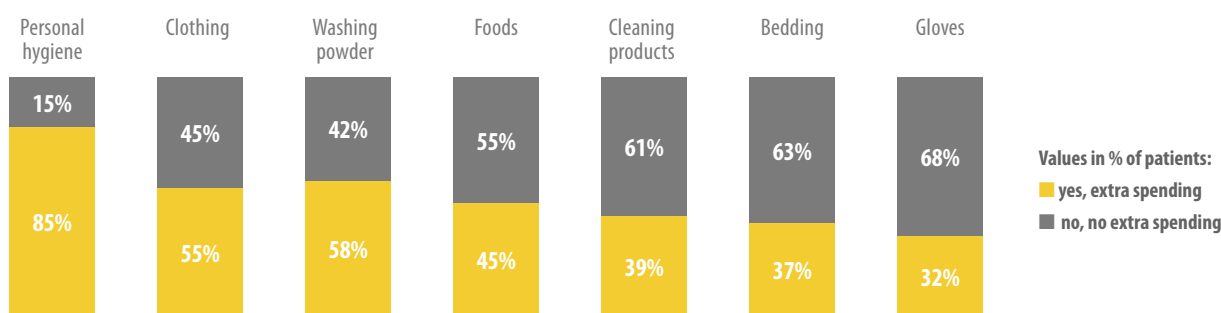
Atopic eczema patient from Spain

Prevention is costly for patients

On top of the annual average € 927.15 on healthcare expenses, atopic eczema patients also need to spend extra money on direct everyday necessities such as personal hygiene products (+18%/month) because they cannot use standard, particularly the perfumed, cheapest options. They also need to allocate additional money every month to purchase washing powder, clothing, cleaning products, food, bedding and gloves to protect bleeding skin, and also because certain materials and chemicals in products further irritate the skin, or cause a flare up. Only 7% have no extra spending at all on everyday necessities.

Patients in the Netherlands, who responded the survey, have a lesser increase on expenditure in food but more in cleaning products compared with other countries. Patients in Nordic countries and the Czech Republic, who responded the survey, incur higher expenses for their everyday necessities, except for personal hygiene.

Table 6. My extra spending in different areas



Average increase in % per month in everyday necessities

Only 7% of the patients have no extra everyday life spending at all.

«The things and tools needed for eczema are expensive, they should be covered by the insurance company.»

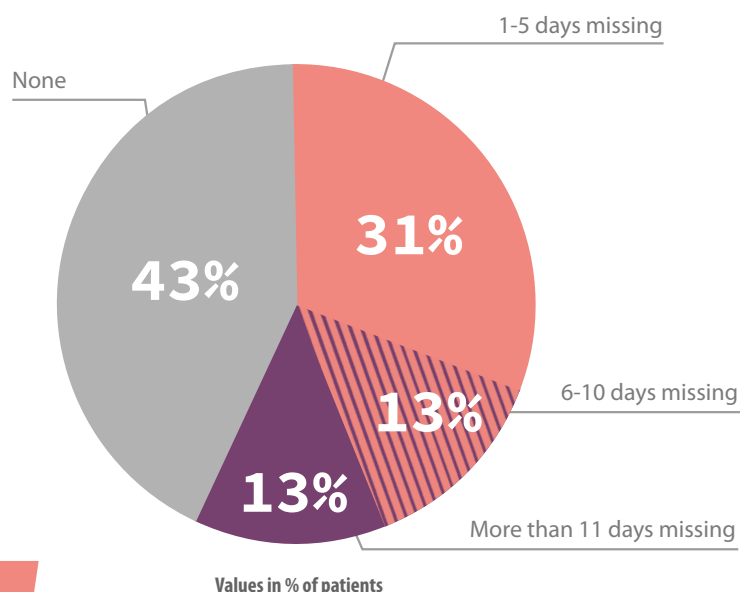
Severe atopic eczema patient from Czech Republic

Atopic eczema leads to sick leave

Across all the countries, over half of the people with severe atopic eczema (57%) have missed at least one day at work or studying in a year. 26% of them missed more than one week of work and 13% missed 11 days or more. Those who have been recently diagnosed with atopic eczema, those currently receiving systemic treatment, those who are less satisfied with their treatment and those having moderate or severe symptoms at the time of their interview miss the most days at school or work.

Sick leave due to atopic eczema is significant. One in three atopic eczema patients in Germany, France, Spain, Italy and United Kingdom, had been prevented from working or studying in the week before their interview because of their eczema. 76% of Danish patients, 40% Czech patients, 29% of Dutch and 29% of Swedish patients, responding the questionnaire, lost between one and ten days per year due to atopic eczema. In addition, 29% of the respondents from the Czech Republic and 20% from Germany lost more than ten days per year due to atopic eczema.

Figure 10. The days I have missed at work or school due to atopic eczema this year



«Employers should care more for colleagues with atopic eczema. We often need to go to the doctor during working hours.»

Severe atopic eczema patient from Italy

«I scratch myself and it means complications, I cannot swim and do sports. I need to spend more money on clothes and cannot have tight clothes nor fully covering shoes. Work clothes can be a problem, the ability to adapt them. I am worried when I'm looking for a job because you cannot wash your hands as often as may be needed. The employment service needs to understand that I cannot search for all jobs.»

Severe atopic eczema patient from Sweden

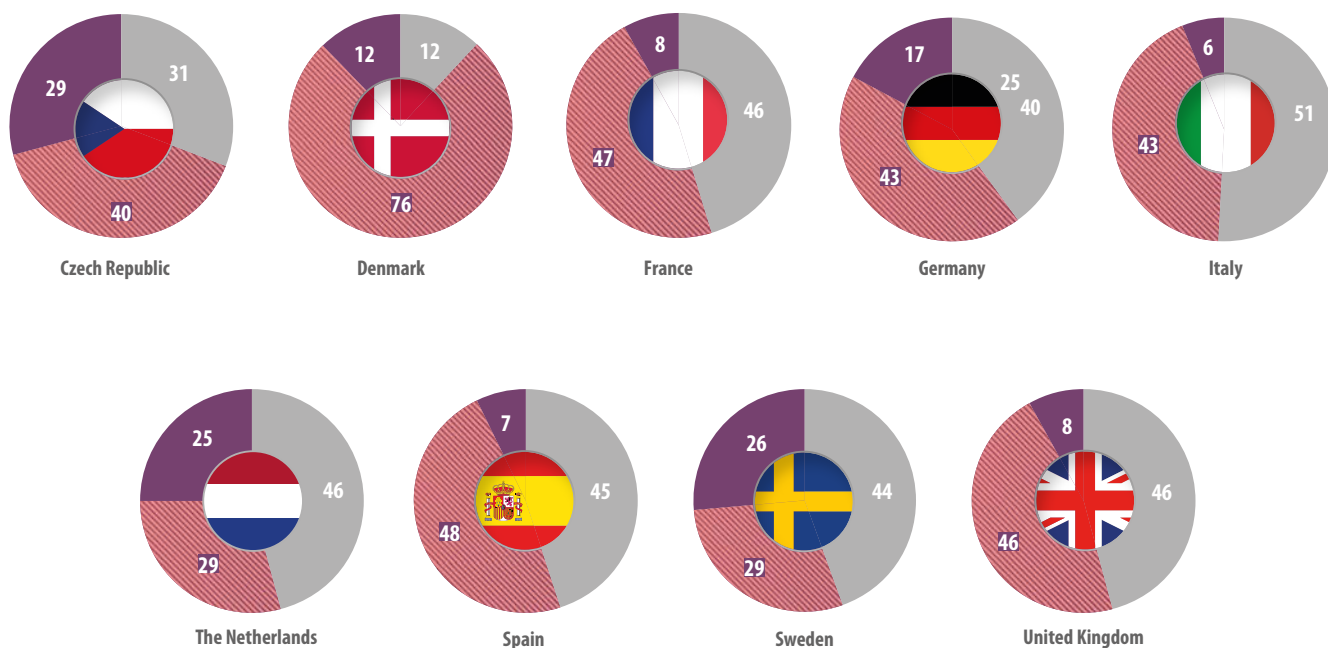
«It's very annoying to have atopic eczema, and it can lead to sick leave. Politicians should tell that it is not contagious, and that we do much to not bother others with it.»

Atopic eczema patient from Denmark



In this context, sometimes atopic eczema patients are prevented from work or studying because they are hospitalised. In Germany, France, Italy, Spain and the UK, around 20-30% of the respondents from these countries were hospitalised over the last 12 months because of their atopic eczema condition. Even so, half of the Dutch and Danish and three in five Swedish respondents spent several days in the hospital over the last 12 months.

Table 7. My days of sick leave due to atopic eczema by country



Values in % of days of sick leaves taken by patients because of atopic eczema: ■ none ■ 1-10 days ■ more than 10 days

Atopic eczema leads to at least 1 day of sick leave for 57% of the patients.

«Atopic eczema is an everyday fight and this is underestimated. I must always keep it in mind and can never know what I will have the next day. Emotionally it is burdensome that I cannot work and cannot contribute to society. I am a cost and a burden for society. I cannot give anything back. You cannot make a promise. Not even a volunteer job. I always have the feeling of falling short.»

Atopic eczema patient from the Netherlands



CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS

In Europe, almost 10% of atopic eczema patients suffer from a severe condition. Our study shows that adults with a severe form of atopic eczema are suffering more than would be considered acceptable. Many (23%) do not have an optimistic view on their life with eczema, 45% had serious eczema symptoms at the time of the interview, and despite care, they had almost every day a dry or rough skin (36%), itchy skin (28%), cracked skin (17%) and felt their skin was flaking off (20%).

Patients need help with the utmost urgency. Not only our survey expresses a latent need for treatment improvements (only 15% of the patients are highly satisfied with their current treatment), but also better support to actually access care: people with severe atopic eczema spend extra money on healthcare expenses, on average € 927,12 annually, and have extra spending on everyday necessities, such as personal hygiene which cost 18% more on average per month.

The more severe the atopic eczema symptoms, the greater the impact on life. For 45% of the patients interviewed, their disease influenced their relationships, sexual life and hobbies, in the week before the interview. What's more, 38% of the respondents declared feeling impaired at work because of their skin.

The emotional burden atopic eczema patients carry constantly is exhausting: 1 in 4 patients feel they cannot keep atopic eczema under control, itching drives them crazy (57%) and they feel guilty about scratching (39%). Our survey shows that 1 in 4 patients sometimes unable to face life, especially among those aged 50+ years, and patients dealing with severe skin conditions. Moreover, the longer patients suffer from atopic eczema, the worse their ability to face life becomes: 43% of the patients suffering for 40 years and longer experienced a significant number of times when the disease compromised their ability to face life.

Patients are constantly looking for information (70%) on new and more efficient treatments that would help them live better lives. It is critical to relieve the physical, psychological and emotional burden of atopic eczema. Patients believe more efforts are needed to:

- Improve the acceptance and understanding of the disease among the public, healthcare professionals, national and EU policy-makers: atopic eczema is not a minor condition, but a serious chronic disease, a burden for the life of affected patients.
- Help patients to better understand their own chronic condition, for example explaining in more detail the different treatment options, to enable patients to take informed decisions about their treatment together with their trusted physician.
- Provide access to better and affordable healthcare for patients, with higher financial support from health insurances: atopic eczema patients incur high costs to treat and manage their disease. Better reimbursement policies would at least reduce this collateral burden in their lives.
- Invest in research to develop new treatments: better therapies are needed to manage the disease more effectively and ultimately cure it.

Patients wish more awareness and better education among the general public to make clear that atopic eczema is neither an infectious nor contagious disease. A better understanding of the disease could restrain people from staring at atopic eczema patients, some with obvious disgust at their appearance.

The positive message arising from our report is that despite being a very personal disease, people with severe atopic eczema are not alone: 53% of the respondents are members of a support group (or are benefitting from the information these groups provide) or communicate with other patients thanks to dedicated groups on social media. Many patients also feel supported by their doctors, with 91% of the respondents declaring to trust them.

RECOMMENDATIONS

Atopic eczema is an exhausting and limiting disease for patients, who not only declare living with unbearable symptoms all their lives, but also suffer from the lack of understanding about a disease that puts them in very uncomfortable situations almost daily.

The following recommendations arise from the messages participants in our survey chose to convey to the different audiences listed below:

Recommendations to healthcare professionals and researchers, so that the burden patients bear is shared, eased and removed.

Although atopic eczema patients who participated in our survey declared trusting their doctors, they feel not being taken seriously by them. Their sentiment goes beyond a personal impression, reflecting instead a systemic neglect of some dimensions of atopic eczema.

Patients recommend healthcare professionals, especially physicians:

- not to just focus on the skin symptoms but to pay more attention to the people living with atopic eczema, because humanity and empathy can help patients live better lives,
- to treat the disease with coherence, reduce the prescription of corticosteroids specially among children and understand the patients who might not want to take some medication,
- to prescribe alternative methods to treat the disease, when possible, and recommend going to the sea and spa, and travel to healing climates,
- to work in multidisciplinary teams, connecting dermatology, immunology and allergy in the check-ups,
- to prescribe other medical disciplines such as psychology to help guide patients relieving the mental suffering and avoid depressions, but also to give good moral support to parents who feel helpless facing this disease.

Patients are proactively looking for new solutions that might help them but they are disappointed about the lack of medical breakthroughs around atopic eczema. They do not understand why the biggest organ in the body is not of interest for research.

Patients recommend researchers:

- to launch broad investigations around the human skin, moving from symptom control to the elimination of the causes,
- to consider how new therapies beyond conventional medicine can help patients,
- to investigate why this disease increases more and more.

Many patients are concerned about the important side effects of treatments they take during long periods.

Patients recommend the pharmaceutical industry:

- to launch new clinical trials for new treatment options,
- to search for alternatives that do not sensitize the skin.

Recommendations to EFA member associations, our partners and other skin associations, for use in their work to improve the lives of people with atopic eczema.

Atopic eczema is a disease with a double burden, not only the symptoms can be unbearable for patients, but also the perception others have about patients can be socially and mentally painful.

Patients recommend the associations representing them to use the findings in this report:

- to inform about the disease to move away from the idea that atopic eczema is a contagious and self-inflicted disease, so that their illness is respected,
- to launch awareness raising campaigns about atopic eczema as a serious chronic skin disease to reduce the discrimination suffered by patients based solely on the looks, so that the illness is better recognized by society,
- to help patients break their loneliness through support groups, especially among children, so that they live normal lives despite the obviousness of the illness.

EU policy makers to paint a picture for Europe and consider and recommend solutions.

Atopic eczema is a disease that can also be triggered by allergies, by a food intolerance or by the contact of the skin with the environment.

Independently of the country surveyed, patients overwhelmingly referred to the many burdens they cope with to prevent their symptoms and to access to care. They highlighted in many cases that the disease is not taken seriously by public authorities.

They came up with clear recommendations for the European policy makers:

- to increase the recognition of skin diseases, notably atopic eczema, as a serious chronic illness with a high social and emotional impact,
- to reduce inequalities among European patients promoting consistency in the health care (multidisciplinary approach), increasing reimbursement among Member States, and decreasing bureaucracy for patients,
- to promote quality healthcare for allergy and airways diseases, to increase the number of specialised physicians and reduce the waiting list in medical centres,
- to better link atopic eczema with the European lifestyle through research funding both on the things that can worsen the skin directly (food, cosmetics, stress) and indirectly (like the outdoor air pollution and the materials used in indoor environments such as flowers, perfumes, soaps, detergents).

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