

Quality of Care and Management of Atopic Dermatitis Across Different Levels of Healthcare—A Survey-Based Patient Experience

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Abstract

Atopic dermatitis (AD) is a chronic and fluctuating disease. Optimal management of AD and related comorbidities requires seamless coordination across multiple layers of the healthcare system. The objective of this survey was to explore patients' experiences with current management of AD. Out of 251 responders to this anonymous survey, 76% reported to have moderate or severe AD. Sixty-nine percent with moderate and 45% with severe AD were followed up at primary care level only. Use of advanced systemic treatment options was rare, and the majority experienced itch (97%), dry skin, rash, negative impact on self-esteem and comorbidities despite ongoing treatment. Only 36% received a treatment plan, more often in secondary (78.3%) than primary care (25.0%). Forty-three percent did not know who was responsible for their follow-up and 54% felt no one was responsible. Treatment options were commonly not known or understood. The survey results demonstrate undertreatment, lack of a holistic approach for management of AD. A national pathway including clear referral criteria and timelines can streamline management of AD across multiple levels of the healthcare system.

Keywords

patient experience, atopic dermatitis, patient survey, itch, treatment plan

Key Points

- Majority of atopic dermatitis (AD) patients were informed by healthcare professionals that their AD will disappear as they grew up.
- Majority of AD patients with moderate to severe disease were followed up at primary care level only and did not receive a treatment plan. However, those who received a treatment plan were more satisfied with their current follow-up in healthcare.
- Majority of AD patients experienced itch and found it quite or very difficult to manage despite ongoing treatment. Considerable proportion also reported fatigue, insomnia, depression, and anxiety.
- The greatest concern related to AD was that the symptoms will never settle. The use of advanced treatment options for AD was low.

Introduction

Atopic dermatitis (AD) is one of the most common chronic diseases affecting 10%-20% of the population in developed countries.¹ Although AD usually starts in childhood, it is increasingly recognized as a disease that persists into or begins in adulthood.² As a relapsing inflammatory skin

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condition, AD is characterized by intense itching and recurrent eczematous lesions.¹

The pathophysiology of AD is genetically determined, and the disease cannot be completely cured.³ Thus, the management of the disease focuses to improve symptoms and achieve long-term disease control, as outlined in national and international guidelines.^{4,5} Basic emollient therapy is the cornerstone of every treatment of AD.⁶ Topical corticosteroids remain the first-line anti-inflammatory treatment and topical calcineurin inhibitors are used for reactive flares.⁵ For more severe forms of AD, ultraviolet radiation and systemic therapy including biologics and Janus kinase (JAK) inhibitors can be used.⁵ Norwegian recommendations for the use of biologics and JAK inhibitors suggest the following criteria for severity of disease; eczema severity and area index ≥ 21 and patient-oriented eczema measure ≥ 17 and dermatology life quality index ≥ 11 in patients ≥ 16 years, and Children's dermatology life of quality index ≥ 11 in patients 6-16 years.⁴ In addition, there is a requirement for the use of cyclosporin or other conventional systemic treatment for at least 3 months before initiation of biologics or JAK inhibitors in patients fulfilling the above-mentioned disease severity.⁴

With chronic nature and variable clinical manifestations and comorbidities, AD is increasingly recognized to have substantial psychosocial burden on patients.⁷ In the Global Burden of Disease study, AD ranks 15th among all nonfatal diseases and has the highest disease burden among skin diseases as measured by disability-adjusted life-years.⁸ The disease is associated with multiple comorbid allergic, mental health, infectious, and cardiovascular comorbidities, which should be accounted for in clinical decision making.⁹ Moderate to severe AD has been associated with decreased quality of life (QoL),^{10,11} and substantial financial impacts even in countries with government-funded healthcare systems.^{11,12} Multiple healthcare providers are involved in the treatment and follow-up of patients with AD.⁵ For such a chronic, recurrent, and debilitating inflammatory disease well-functioning referral process with good collaboration and coordination between primary and secondary healthcare, correct severity assessment, timely referral to secondary healthcare along with timely and evidence-based treatment are key elements for holistic and successful management of the disease. However, no research has been done on how patients perceive their treatment, follow-up, and care in the Norwegian healthcare setting. For a disease like AD that varies over time, at times requires management across different levels and specialties of healthcare, insights and patient perspective studies are essential to identify potential areas of improvement. The purpose of the study was to investigate real-life experiences of patients with AD as managed by the multiple layers of the Norwegian healthcare system, to gain a better understanding of the current care pathway, identify challenges, gaps, and potential areas of improvement in treatment, education, and follow-up of patients with AD.

Method

The questionnaire was developed in collaboration with the Norwegian patient organization and a hospital-based specialist in dermatology. The survey was validated in 2 rounds of interviews including 8 patients with AD representing equal gender, age, and different duration and severity of disease. The anonymous survey was posted on the webpage of the Norwegian patient organization and as advertisement on webpages for disease awareness. To maintain anonymity and to reduce selection bias, recruitment through treating healthcare providers was not permitted. Data were collected between November 2021 and March 2022. All participants consented for publication of results at aggregated level before proceeding with the survey. Data privacy impact assessment was performed. For anonymous surveys, there is no possibility to identify any individual responses. According to the Norwegian Regional Committee for Medical and Health Research Ethics, no ethical approval is required as the health survey-based research did not concern any identifiable human subjects, their individual data, or biological material. All data were self-reported by patients. Participants were required to be above 18 years old to respond to the survey, and parents could answer on behalf of their children with AD.

The patient survey included questions related to disease-specific variables such as treatment, symptoms, comorbidities, and the impact of the disease on everyday life. Furthermore, the survey included a set of questions on perceived health and quality of care as well as questions on how well the respondents felt they had been informed and followed up by healthcare providers. The survey data were analyzed with Questback tools (Questback, Oslo, Norway), Microsoft Excel (Microsoft Corporation, Redmond, WA) and GraphPad Prism 9.4.1 (GraphPad Software, San Diego, CA). The data consisted of categorical and continuous variables. The data collected are descriptive and not designed to test any specific hypothesis.

The severity of AD was self-reported by the respondents based on the following definition: Mild AD (eg, dry areas of skin, occasional itch, redness in small areas of skin, less than 5% of your body surface involved, no significant impact on QoL); Moderate AD (eg, dry areas of skin, repeated itch, redness, possibly also skin breakage/thickening in 5%-30% of your body surface, mild AD but with significant impact on QoL); Severe AD (eg, dry skin, persistent itch, widespread redness, skin eczema/rash, significant thickening of the skin, bleeding, crusting, discoloration, more than 30% of your body surface involved).¹³ Mann-Whitney *U* test was used to compare follow-up satisfaction of respondents with and without treatment plan. Spearman correlation coefficient analysis was used to assess the relationship between itching and insomnia severity.

Results

Background of Respondents

A total of 251 responses were received. Background information of the respondents is presented in Table 1. Most of the respondents were women (81.6%), above 18 years old (87.6%) and worked full- or part-time (70.5%) (Table 1). Majority (75.9%) of respondents reported to have moderate or severe AD (Table 1). Allergies, asthma, depression, and anxiety were common comorbidities (Table 1).

The mean age at the time of AD diagnosis was 7 years. Of the respondents diagnosed under 12 years old (82%), 80% were told that AD will go away when growing up. The diagnosis was most often given by general practitioner (GP) (39.0%) or dermatologist in public healthcare (28.1%). A total of 71.5% had received referral to a specialist due to AD, which took over 3 months in most of the respondents (58.9%). Because not referred to a dermatologist in time,

53.0% had tried to find alternative treatment or advice at their own cost. Other diseases/comorbidities related to AD were not asked for or investigated in 41.8% of the respondents by the healthcare providers. Vast majority of respondents were not familiar with treatment guidelines (93.0%), timelines for referrals to specialists (94.4%), and reimbursement rights (70.0%) as stated in the national guidelines.

Follow-up and Treatment Plan

Follow-ups of the respondents are shown in Figure 1A for all the respondents and for respondents stratified by disease severity. Nearly 2 of 3 of all the respondents were followed up in primary healthcare, followed by dermatologists in private practice and hospitals (Figure 1A). During the last 12 months, 44.8% had not seen a doctor or nurse. On average, GP was seen twice (24.5%) or once (24.5%) a

Table 1. Basic Characteristics of Study Participants.

	N = 249	Mild, n = 60 (24.1%)	Moderate, n = 138 (55.4%)	Severe, n = 51 (20.5%)
Sex, n (%)				
Male	39 (16.7)	9 (16.7)	15 (11.6)	15 (30.0)
Female	190 (81.5)	44 (81.5)	111 (86.0)	35 (70.0)
Age, years, n (%)				
Under 12	18 (7.4)	8 (13.6)	8 (6.0)	2 (4.0)
12-18	13 (5.3)		8 (6.0)	5 (10.0)
19-24	14 (5.8)	2 (3.4)	8 (6.0)	4 (8.0)
25-34	46 (18.9)	10 (16.9)	27 (20.1)	9 (18.0)
35-44	61 (25.1)	12 (20.3)	39 (29.1)	10 (20.0)
45-54	48 (19.8)	16 (27.1)	23 (17.2)	9 (18.0)
55-64	30 (12.3)	10 (16.9)	14 (10.4)	6 (12.0)
65-74	12 (4.9)	1 (1.7)	6 (4.5)	5 (10.0)
Above 74	1 (0.4)		1 (0.7)	
Employment status, n (%)				
Full-/part-time work	176 (70.7)	45 (75.0)	96 (69.6)	35 (68.6)
Pensioner	16 (6.4)	3 (5.0)	8 (5.8)	5 (9.8)
Student	19 (7.6)	4 (6.7)	12 (8.7)	3 (5.9)
Unemployed	4 (1.6)		2 (1.4)	2 (3.9)
None of the above	34 (13.7)	8 (13.3)	20 (14.5)	6 (11.8)
Age at diagnosis, years, n (%)				
Under 1	62 (24.9)	12 (20.0)	38 (27.5)	12 (23.5)
1-10	141 (56.6)	35 (58.3)	79 (57.2)	27 (52.9)
11-20	19 (7.6)	8 (13.3)	6 (4.3)	5 (9.8)
21-30	8 (3.2)	1 (1.7)	7 (5.1)	0 (0.0)
Above 30	19 (7.6)	4 (6.7)	8 (5.8)	7 (13.7)
Comorbidities, n (%)				
Pollen allergy	145 (58.2)	33 (55.0)	79 (57.2)	33 (64.7)
Food allergy	121 (48.6)	19 (31.7)	68 (49.3)	34 (66.7)
Animal allergy	118 (47.4)	28 (46.7)	61 (44.2)	29 (56.9)
Asthma	74 (29.7)	12 (20.0)	45 (32.6)	17 (33.3)
Chemical allergy	60 (24.1)	12 (20.0)	34 (24.6)	14 (27.5)
Allergic rhinitis	52 (20.9)	9 (15.0)	27 (19.6)	16 (31.4)
Depression	44 (17.7)	7 (11.7)	26 (18.8)	11 (21.6)
Anxiety	38 (15.3)	7 (11.7)	23 (16.7)	8 (15.7)

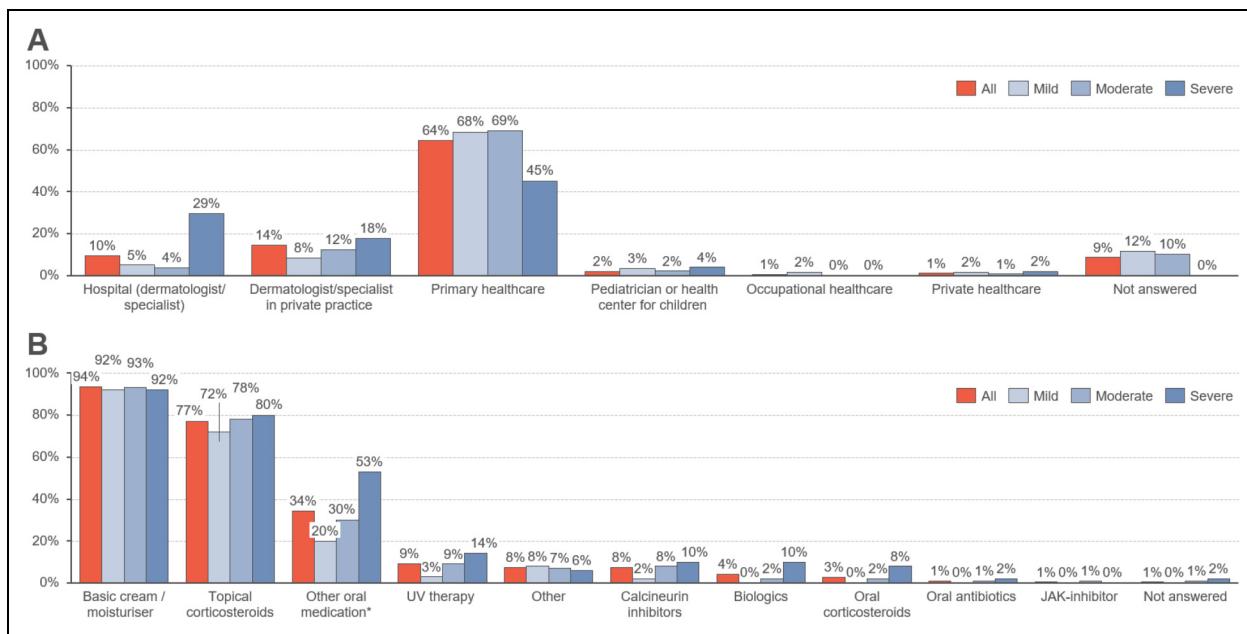


Figure 1. Self-reported follow-up and treatment. (A) Current follow-up of all the respondents and respondents stratified by disease severity, and (B) Current treatment of respondents stratified by disease severity. *Such as antihistamine, cyclosporine (sandimmun), azathioprine, methotrexate, alitretinoin (Toctino).

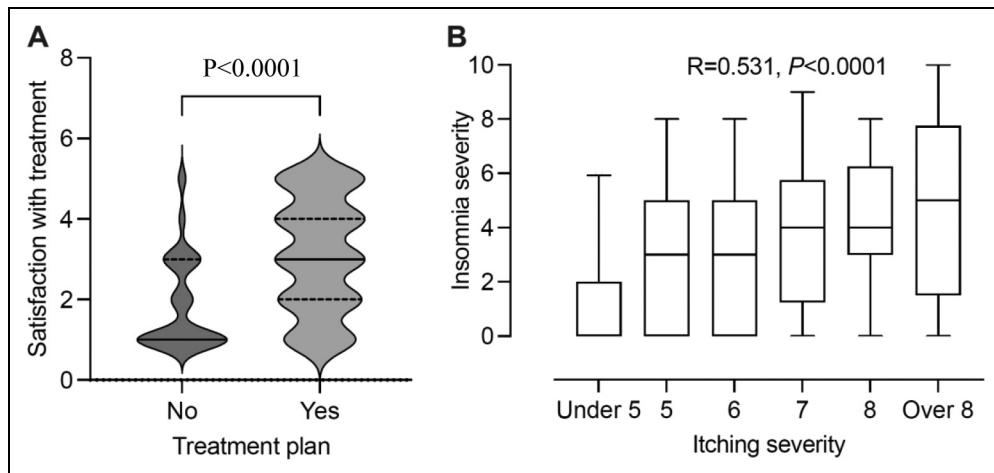


Figure 2. Relationship between treatment plan and satisfaction with follow-up, and between itching and insomnia severity. (A) Satisfaction with follow-up was scored from 1 to 5 (1 = very dissatisfied, 5 = very satisfied). In the violin plot, the width of the curve corresponds to the approximate frequency of answers with the corresponding score, solid line median, and dashed lines interquartile range. Mann-Whitney U test was used to compare follow-up satisfaction of respondents with and without treatment plan. (B) Spearman correlation coefficient analysis was used to assess the relationship between itching and insomnia severity. Data are shown as box plot where box represents the interquartile range, line within boxes median, and whiskers 95% confidence intervals. R , Spearman correlation coefficient.

year, while dermatologist was seen less frequently (44.1% seen at least once a year; severe 69.0%, moderate 36.9%, mild 15.0%). Merely 35.5% had been presented with a treatment plan (severe 54.9%, moderate 29.0%, mild 28.3%) by hospital dermatologist (derm.) 78.3%, private derm. 62.5% and primary care 25.0%. Almost half (48.8%) were dissatisfied with the way they were currently followed up in healthcare (severe 51.0%, moderate 50.0%, mild 40.0%; hospital

derm. 39.1%, private derm. 50.0%, primary care 51.9%). Those who had received a treatment plan were significantly more satisfied ($P < .0001$) with their current follow-up in healthcare (Figure 2A). Forty-three percent of respondents did not know who is responsible for their healthcare, and 54.0% felt that no one is responsible for their care (severe 54.0%, moderate 54.0%, mild 54.3%; hospital derm. 45.5%, private derm. 40.6%, primary care 58.2%).

In opinion of respondents, the most important topics to be discussed during appointments were pharmacological treatments of AD (mean importance 4.57 on 5-point scale), new treatments for AD and the development of treatments (4.52), and progression of AD as a disease (4.51). Only 17.6% felt they get enough support from the healthcare professionals and only 24.8% felt they get enough time to talk to the professionals during the appointments. A total of 74.0% felt they were given the same advice by healthcare providers repeatedly (severe 80.0%, moderate 73.2%, mild 61.7%). Respondents would like to get more information, especially on the treatment options of AD (81.5%), more information and education about AD (54.0%), and about the development of new treatment options for AD (54.0%).

Medication

Current self-reported treatments are shown in Figure 1B for all the respondents stratified by disease severity. The most common treatments were basic creams/emollients (93.5%) and topical corticosteroids (77.1%), while advanced treatment options such as biological medications and JAK inhibitors were used only rarely (Figure 1B). Seventy percent did not know that advanced treatment can only be prescribed by a specialist in dermatology (severe 51.0%, moderate 71.7%, mild 81.7%). Dissatisfaction with treatment was experienced by 22.4%, and the most common reason for dissatisfaction was ineffectiveness for AD symptoms (69.8%). Over half (51.9%) felt they did not understand the available treatment options for their disease (severe 38.8%, moderate 62.0%, mild 33.9%; hospital derm. 22.7%, private derm. 53.2%, primary care 57.3%). Almost two-thirds (66.4%) stated they deviated from doctor's instructions on medication at least sometimes. Almost half (47.7%) were dissatisfied with the overall treatment they had received, and a similar proportion (49.3%) were not confident how their treatment will continue in the future. Only 36.1% felt they were currently in a good treatment balance overall (severe 21.6%, moderate 34.8%, mild 42.7%).

Symptoms, Comorbidities, and Impact on Life

Itch was the most experienced symptom, and almost all respondents (96.7%) had experienced it during the past year despite treatment (Table 2). Other commonly experienced skin symptoms included dry skin (94.4%) and rash (91.1%). Itch had occurred often or continuously during the past 12 months in 74.8% of the respondents, and it was also considered as the most severe symptom; 74.5% found it quite or very difficult to manage (severe 98.0%, moderate 76.8%, mild 54.0%). Other than skin symptoms, comorbidities due to AD were also common: Fatigue or tiredness was experienced at least occasionally by 65.0% of the respondents, insomnia by 55.1% of the respondents (severe 80.4%, moderate 56.5%, mild 21.7%), and depression or anxiety by 29.0% of the respondents. The severity of

insomnia was significantly correlated with the severity of itching ($R = 0.531$) (Figure 2B).

With respect to other aspects of life, respondents experienced that AD had the most significant impact on self-esteem (61.9% felt AD had at least a moderate impact [severe 84.3%, moderate 65.2%, mild 35.0%]), career and working life (48.2%), and ability to do housework (52.2%), while only mild or no impact was experienced on relationships with friends and family (18.9%), relationships and sexuality (25.7%), and education (24.9%). The greatest concern related to AD was that the symptoms will never settle (57.3% felt at least quite concerned). Other common concerns were that children might inherit AD, and that symptoms of AD might not get better or instead get worse.

Discussion

The present survey-based study reveals shortcomings in treatment, follow-up, and referrals of patients with moderate to severe AD as well as lack of proper communication between patients living with AD and the healthcare system. Considerable proportion of respondents with self-reported moderate and severe disease reported they were primarily followed up at primary care level. Majority of respondents did not receive a proper treatment plan adding to uncertainty. Significant proportion of patients experienced AD-related symptoms and comorbidities despite ongoing treatment. Assessment of comorbidities was in general not included in the follow-up adding to the complexity of the management of AD across different layers of the healthcare system.

The most difficult symptoms experienced by respondents were itch, dry skin, and rash. Itch in particular was considered severe, and almost all experienced it despite treatment and was equally frequent across severity of AD. Being ranked as the most disturbing symptom, which is also correlated with sleep disturbance, suggests Itch should be addressed thoroughly in the patient-healthcare provider communication. Itch and related sleep problems have also previously been reported as the most frequent symptoms in AD patients.^{14–16} Loss of sleep may in turn cause daytime sleepiness, which could further adversely affect the mood and mental health of patients with AD.

The impact of AD on mental health is well known. Previous studies found that AD patients had significantly lower mental health scores and impaired QoL, causing overall high burden to patients.^{17,19} This survey confirms the previous findings and shows that depression or anxiety increases numerically with increasing severity of AD. The numerical increase of comorbidities with severity of AD is observed with nearly all comorbidities mentioned in Tables 1 and 2. Especially increasing occurrence of sleep disturbances, mental health issues, and fatigue in Table 2 deserves to be discussed in a patient-physician dialog and addressed in order to provide a more holistic approach toward treatment of AD. A considerable proportion of respondents reported moderate effect of AD on self-esteem, and the impact was highest

Table 2. Symptoms Experienced Due to Atopic Dermatitis.

	N = 249	Mild, n = 60 (24.1%)	Moderate, n = 138 (55.4%)	Severe, n = 51 (20.5%)
Skin symptoms experienced				
Symptoms experienced in the last 12 months despite treatment, n (%) experienced				
Itchiness	240 (96.8)	58 (96.7)	132 (96.4)	50 (98.0)
Dry skin	235 (94.8)	55 (91.7)	131 (95.6)	49 (96.1)
Rash	224 (90.3)	49 (81.7)	124 (90.5)	51 (100.0)
Redness of skin	209 (84.3)	47 (78.3)	118 (86.1)	44 (86.3)
Breakage of skin	192 (77.4)	40 (66.7)	113 (82.5)	39 (76.5)
Skin oozing	131 (52.8)	20 (33.3)	80 (58.4)	31 (60.8)
Thickening of skin	125 (50.4)	17 (28.3)	71 (51.8)	37 (72.5)
Crusting of skin	124 (50.0)	16 (26.7)	71 (51.8)	37 (72.5)
Skin bleeding	112 (45.2)	13 (21.7)	67 (48.9)	32 (62.7)
Skin infection	85 (34.3)	11 (18.3)	43 (31.4)	31 (60.8)
Skin symptom severity				
Severity of symptoms of atopic dermatitis, mean (SD) in scale 1-5				
Itchiness	4.1 (1.0)	3.4 (1.0)	4.1 (1.0)	4.8 (0.5)
Dry skin	3.9 (1.0)	3.6 (1.1)	4.0 (1.0)	4.2 (0.9)
Rash	3.8 (1.0)	3.2 (0.9)	3.8 (1.0)	4.4 (0.7)
Redness of skin	3.6 (1.3)	2.9 (1.3)	3.8 (1.3)	4.0 (1.2)
Breakage of skin	3.3 (1.1)	3.0 (1.0)	3.4 (1.1)	3.6 (1.1)
Skin oozing	2.7 (1.5)	2.0 (1.3)	2.8 (1.5)	3.3 (1.4)
Thickening of skin	2.6 (1.4)	1.8 (1.1)	2.7 (1.4)	3.2 (1.3)
Crusting of skin	2.6 (1.3)	1.8 (1.1)	2.7 (1.3)	3.3 (1.1)
Skin infection	2.5 (1.5)	1.8 (1.1)	2.5 (1.5)	3.3 (1.4)
Skin bleeding	2.5 (1.4)	1.7 (1.1)	2.6 (1.3)	3.4 (1.2)
Other symptoms/comorbidities				
Other symptoms experienced during last 12 months due to atopic dermatitis, n (%) experienced				
Insomnia	132 (53.0)	13 (21.6)	78 (56.5)	41 (80.3)
Waking up during the night	132 (53.0)	16 (26.6)	78 (56.5)	38 (74.5)
Pain	136 (54.6)	15 (25.0)	80 (57.9)	41 (80.3)
Fatigue/tiredness	156 (62.6)	24 (40.0)	92 (66.6)	40 (78.4)
Anxiety	64 (25.7)	5 (8.3)	38 (27.5)	22 (43.1)
Depression	64 (25.7)	5 (8.3)	37 (26.8)	22 (43.1)

for those with severe disease. The International Study on Life with Atopic Eczema found major impacts of AD on self-esteem: 36% said AD affects their self-confidence.¹⁸ For primary care, new AD-specific criteria and guidelines including symptoms other than rash only, such as itch, insomnia, psychological impact, and QoL measures should be developed and taken into use for better patient communication and improvements in referrals to specialist care.

Most use only topical creams and corticosteroids, and advanced treatment is used only rarely. Treatment options available are commonly not known or understood, and many have no clear information of who is responsible for follow-up of their disease. Interestingly, treatment options were unclear especially for patients with moderate disease as compared to those with mild or severe disease. This might be related to follow-up; compared to those with

severe disease, patients with moderate disease were rarely followed up by specialists and may thus be undertreated. The results illustrate shortcomings in treatment, follow-up, and continuity of treatment for AD patients, especially for those with moderate disease.

The present study identified several knowledge gaps related to treatment options, treatment guidelines, and timelines, as well as reimbursement rights. Majority felt they do not understand treatment options for while at the same time treatment options were found as the most important topic to be discussed during appointments. Indeed, clear majority felt they do not get enough support to their treatment from the professionals, and only a few felt they have enough time to talk to the professionals during the appointment. Most of the respondents lack a treatment plan, especially those followed up in primary care while the corresponding

proportion was much lower in specialist care. A treatment plan with regular follow-up and discussion of most common symptoms and comorbidities could be sufficient to cope with many of these shortcomings, supported by the observation that those with treatment plan were clearly more satisfied with their current follow-up than those without. Educational efforts are required for patients and professionals at the primary care level, which have already been emphasized in several expert panels.^{5,20}

Limitations

The present study has some limitations. First, as with other survey-based studies, recruitment was limited through social media advertisements and biases in sample selection can't be excluded. Self-reported disease severity cannot be clinically verified and may pose a selection bias toward respondents experiencing a flare at the time of the survey. Most of the respondents reported suffering from moderate or severe AD and thus be subjective and the results may not be applicable to patients with mild disease and differ also from a physician assessment. Similarly, treatments received, and place of follow-up were self-reported and can thus be influenced by subjective perceptions.

Conclusion

In conclusion, the survey provides valuable insights into patient perspectives on the current management of AD across different levels of the healthcare system. It reveals which AD-related symptoms, comorbidities, and concerns are most important for patients and should be addressed by a unified healthcare system. A shared treatment plan across different levels and specialties including the most important aspects of AD symptoms and related comorbidities could streamline management of AD. Current healthcare as experienced by patients, especially with moderate to severe disease, does not facilitate a holistic approach toward management of AD including its long-term implications. A national care pathway including specific criteria and timelines for referrals, treatment, and follow-up of AD patients, already from the primary care level could improve the patient experience.

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Declaration of Conflicting Interests

Randeep Mandla and Synne Ildahl Svendsen are employees of, and shareholders in Pfizer. All other authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

According to Norwegian law, Ethical Committee (REK) approval is not required if the collected data are anonymous and regard

evaluation of health aspects. Home—Insights (rekportalen.no). No ethical approval or advance notice was required as this anonymous survey research did not concern any directly or indirectly identifiable human subjects, personal data, or biological material. This is specified by the Ethical Committee on their submission portal.

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Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the guidance provided by the Norwegian Regional Committee for Medical and Health Research Ethics Home—Insights (rekportalen.no).

Statement of Informed Consent

All respondents agreed to the publication of anonymous results on an aggregated level before proceeding to the survey. No identifiable or personal information or IP addresses were collected in accordance with the guidance of the Norwegian Regional Committee for Medical and Health Research Ethics.

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