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Assessing the Burden of Atopic Dermatitis in Portugal through Patient-Centered Experiences

Avaliação da Carga da Doença Atribuída à Dermatite Atópica em Portugal através de Experiências Centradas no Doente

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ABSTRACT

Introduction: Adult patients and caregivers of children with atopic dermatitis experience high physical, mental, and financial burden in Portugal. We outline the experience of atopic dermatitis management and how the current medical care model impacts patient-centered concerns such as financial burden, quality of life, disease burden, and treatment satisfaction.

Methods: We conducted a survey of 419 Portuguese adults and caregivers of children to capture the experience of managing atopic dermatitis in Portugal.

Results: Respondents reported average satisfaction with treatment, with a mean satisfaction rating of 3.15/5.00 (SD = 0.77). Adults reported slightly better control of atopic dermatitis symptoms (mean = 56.6) than pediatric patients (mean = 55.9, caregiver reported). Nearly 34% of adults and 39% of caregivers of children and adolescents indicated that their healthcare providers asked about their priorities at the last medical visit. Additionally, only 40% of adult patients and 32% of caregivers reported that patient training was offered to them. Respondents seeing dermatologists reported higher satisfaction than those seeing other healthcare providers ($p = 0.01$) but there were no differences in long-term control of symptoms by provider type ($p = 0.85$) when controlling for severity. Portuguese adult patients scored 0.86/1.00 on the EQ-5D (where 0 = death and 1 = perfect health). Financial concern was high as nearly 80% of patients and caregivers reported using savings, borrowing money, and/or reducing spending to cover atopic dermatitis-related costs.

Conclusion: Portuguese patients with atopic dermatitis and caregivers experience financial burden, lower health-related quality of life, higher disease burden, and treatment satisfaction issues with their current medical care. These factors often deteriorate as the disease's severity increases. Providers, researchers and policymakers should focus on better addressing patient-centered concerns for individuals suffering from atopic dermatitis to improve care and health outcomes.

Keywords: Cost of Illness; Decision Making, Shared; Dermatitis, Atopic/epidemiology; Dermatitis, Atopic/therapy; Patient Education; Portugal; Quality of Life

RESUMO

Introdução: Em Portugal, os doentes adultos e os cuidadores de crianças com dermatite atópica encontram-se sobrecarregados com elevadas responsabilidades a nível físico, mental e financeiro. Neste artigo, descreve-se a experiência da gestão da dermatite atópica e o impacto que o atual modelo de cuidados médicos representa a nível dos encargos financeiros, da qualidade de vida do doente, do peso da doença e da satisfação com o tratamento.

Métodos: Realizou-se um inquérito a 419 adultos portugueses e a cuidadores de crianças para conhecer a experiência de gestão da dermatite atópica em Portugal.

Resultados: Os inquiridos referiram uma satisfação média com o tratamento, com um índice de satisfação médio de 3,15/5,00 (DP = 0,77). Os adultos referiram um controlo ligeiramente melhor dos sintomas da dermatite atópica (média = 56,6) do que os doentes pediátricos (média = 55,9, relatado pelo prestador de cuidados). Cerca de 34% dos adultos e de 39% dos prestadores de cuidados de crianças e adolescentes com dermatite atópica indicaram terem sido questionados sobre as suas prioridades na última consulta médica. Além disso, apenas 40% dos doentes adultos e 32% dos prestadores de cuidados referiram que foi oferecida formação aos doentes. Os inquiridos que consultaram dermatologistas relataram maior satisfação do que os que consultaram outros prestadores de cuidados de saúde ($p = 0{,}01$), mas não houve diferenças no controlo a longo prazo dos sintomas por tipo de prestador ($p = 0{,}85$) ao controlar a gravidade. Os doentes adultos portugueses obtiveram uma pontuação de 0,86/1,00 no EQ-5D (em que 0 = morte e 1 = saúde perfeita). A preocupação financeira foi elevada, uma vez que quase 80% dos doentes e prestadores de cuidados referiram recorrer a poupanças, pedir dinheiro emprestado e/ou reduzir as despesas para cobrir os custos relacionados com a dermatite atópica.

Conclusão: Os doentes portugueses com dermatite atópica e os seus cuidadores identificam encargos financeiros, menor qualidade de vida relacionada com a saúde, mais despesas com a doença e problemas de satisfação com o tratamento e com os seus cuidados médicos atuais. Estes fatores tornam-se com frequência mais significativos à medida que a gravidade da dermatite atópica aumenta. Os prestadores de cuidados de saúde, os investigadores e os decisores políticos devem concentrar-se em abordar melhor as preocupações centradas no doente para os indivíduos que sofrem de dermatite atópica, a fim de melhorar os cuidados e os resultados em termos de saúde.

Palavras-chave: Custo da Doença; Dermatite Atópica/epidemiologia; Dermatite Atópica/terapia; Educação do Doente; Portugal; Qualidade de Vida; Tomada de Decisão Partilhada

INTRODUCTION

Atopic dermatitis (AD) is a chronic inflammatory skin disease[1] that is associated with a high physical and mental health burden in patients and caregivers.[2,3] Globally, patients with AD and their caregivers report substantial negative financial impact, lower satisfaction with treatment (especially for those with more severe disease), and lack of

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adequate symptom control.[4] Moreover, individuals with AD may have difficulty accessing specialized care that incorporates their values, preferences, and perspectives.

In Portugal, the estimated prevalence of AD is approximately 0.6% to 3.5%.[3,5,6] Current research suggests that nearly 30% of all individuals with AD in Portugal do not have frequent medical visits and 37% report that their AD causes them to have some degree of disability whereas those who have more severe AD suffer from a greater impact on quality of life.[3] Furthermore, health, psychosocial, and financial outcomes worsen with disease severity.[6] There is a lack of data on the patient and caregiver experience in Portugal on a larger set of patient-centered care factors such as shared decision-making, patient education, treatment satisfaction, access to specialists, and financial impact.

The primary aim of this study is to examine patient-centered experiences among patients and caregivers in Portugal, specifically those linked to health-related quality of life, long-term control of symptoms, shared decision-making, and patient education, satisfaction with treatments, financial impact and psychosocial burden. The results reveal opportunities for innovative approaches to improving the experience of patients and their families.

METHODS

We developed and conducted an anonymous electronic survey with up to 53-items for AD patients and caregivers between March 2023 and July 2023. This study was part of a larger global survey of adults and caregivers of children in eight countries that examined health-related quality of life, long-term control of symptoms, satisfaction with treatments, the financial burden, and the prevalence of patient-centered care.[7] A committee of eleven AD advocacy organizations representing eight countries selected the survey questions covering seven domains of AD management:

1. Treatment satisfaction;
2. Access to medical specialists;
3. Shared decision-making and patient education;
4. Long-term control;
5. Burden of disease;
6. Quality of life;
7. Financial impact.

The survey used the AD Control Tool[8] which is a validated six-question self-assessment tool to measure long-term control of AD symptoms and the EQ-5D[9] to measure quality of life and burden of disease. We adapted treatment satisfaction questions from instruments validated for other diseases (i.e., PsoSat Patient Questionnaire). Where no reasonable instrument was available (i.e., access to medical specialists, shared decision-making and patient education, and financial impact), we developed questions *de novo*. This research was reviewed and approved by Advarra Institutional Review Board (Pro00055632). Respondents were initially asked demographic questions about their age, the child's age (if a caregiver), sex, country of residence and AD severity.

The survey was offered in five languages and distributed by social media, newsletters, and publications of the participating patient organizations. All respondents provided informed consent. Statistical analyses were conducted using R 4.2 (R Core Team, Vienna, Austria). At the end of the survey, participants had the option of entering a drawing for a gift card worth US $100. This paper reports the data provided by Portuguese participants.

RESULTS

Participants

A total of 419 Portuguese respondents completed the survey. Of those, 45% (n = 189) were caregivers to pediatric patients and 55% (n = 230) were adult patients. Respondents were predominantly female: 96% of patients (n = 182) and 85% of caregivers (n = 195). The mean age was 36 years for adult patients and eight years for children (caregiver reported) (Table 1).

Treatment Satisfaction

Overall, respondents reported average satisfaction with treatment, with a mean satisfaction rating of 3.1/5.0 (SD = 0.77) (1 = least satisfied to 5 = most satisfied) as measured by the PsoSat Patient Questionnaire adapted for AD. However, satisfaction was highly dependent upon symptom severity and respondents with the highest AD severity reported the lowest treatment satisfaction at 2.08/5.00 (SD = 1.30) ($p < 0.001$) compared to all less severe groups combined (Fig. 1). Satisfaction was significantly higher when the provider was a specialist ($p = 0.01$), which is driven largely by lower satisfaction with family physicians/ than dermatologists ($p = 0.04$).

Shared decision-making and patient education

Patient-centered medical care was evaluated with two measures: the presence of shared decision-making during the medical appointment and patient training for AD management after the visit that was offered by the provider. Nearly 34% of adults and 39% of caregivers indicated that their providers asked about their priorities at the last medical visit. Additionally, 40% of adult patients and 32% of caregivers reported that patient training was offered to them. By contrast, a minority of respondents (adults: 6%, caregivers: 2%) said their healthcare provider suggested they attend a formal AD training program.

Table 1 – Respondent demographics and survey responses

	Caregiver (n = 189)	**Adult** (n = 230)	**All patients** (n = 419)	***p*-value**
Respondent age				< 0.001
n-Missing	6	5	11	
Mean (SD)	40 (6.7)	36 (10.4)	38 (9.2)	
Range	20 - 63	18 - 69	18 - 69	
Respondent sex	**n (%)**	**n (%)**	**n (%)**	**< 0.001**
Male	7 (3.7%)	35 (15.2%)	42 (10.0%)	
Female	182 (96.3%)	195 (84.8%)	377 (90.0%)	
Patient age				**n/a**
n-Missing	42		47	
Mean (SD)	8.4 (5.5)		25.1 (16.2)	
Range	1 - 25		1 - 69	
Patient sex	n (%)		n (%)	n/a
Male	93 (49.2%)		128 (30.5%)	
Female	96 (50.8%)		291 (69.5%)	
Mean treatment satisfaction 0 - 5 (SD)	3.1 (0.50)	3.2 (0.96)	3.2 (0.77)	0.026
Primary provider	**n (%)**	**n (%)**	**n (%)**	**< 0.001**
Dermatologist	102 (54.5%)	168 (74.0%)	270 (65.2%)	
Pediatrician	51 (27.3%)	0 (0.0%)	51 (12.3%)	
Primary care physician / Family physician	28 (15.0%)	54 (23.8%)	82 (19.8%)	
Allergist	0 (0.0%)	1 (0.4%)	1 (0.2%)	
Dermatology nurse	0 (0.0%)	0 (0.0%)	0 (0.0%)	
Nurse practitioner	0 (0.0%)	0 (0.0%)	0 (0.0%)	
Other	6 (3.2%)	4 (1.8%)	10 (2.4%)	
Shared decision-making	**n (%)**	**n (%)**	**n (%)**	
Asked about priorities	74 (38.9%)	78 (34.1%)	152 (36.3%)	0.43
If asked, priorities included in treatment plan	90 (47.8%)	96 (41.6%)	186 (44.4%)	0.66
Offered training/education	53 (31.7%)	85 (40.1%)	138 (36.4%)	0.093
Recommended > 6 hours training	2 (1.2%)	6 (2.8%)	8 (2.1%)	0.272
Recommended external training	3 (1.8%)	12 (5.7%)	15 (4.0%)	0.055
Mean long-term control				
0 - 100 (SD) ADCT (Adequate control > 70.8)	57.3 (27.6)	56.6 (24.5)	56.9 (25.8)	0.82
Mean burden of disease				
EQ-5D Utility 0 (worst possible) - 1 (best possible) (SD)	n/a	0.86 (0.15)	n/a	n/a
Mean quality of life				
EQ-VAS 0 (worst possible) -100 (best possible) (SD)	n/a	72.6 (17.8)	n/a	
Mean financial worry				
1 = none, 5 = extremely (SD)	2.8 (1.0)	2.6 (0.93)	2.7 (0.99)	< 0.001
Funding AD related costs	**n (%)**	**n (%)**	**n (%)**	
Used savings	49 (26%)	61 (27%)	110 (26%)	0.89
Borrowed money	7 (4%)	17 (7%)	24 (6%)	0.11
Spent less on essentials	31 (16%)	33 (14%)	64 (15%)	0.56
Spent less on nonessentials	84 (44%)	108 (47%)	192 (46%)	0.61
No impact	32 (17%)	54 (24%)	86 (21%)	0.10

Long-term control of symptoms

Long-term control was measured using the AD Control Tool where a score greater than 70.8 indicates adequate control. Respondents with moderate to severe AD scored far below adequate control. Overall, adults reported slightly better control of AD symptoms (mean = 56.6) than pediatric patients (mean = 55.9, caregiver reported). Additionally, and even though long-term control of AD symptoms was negatively associated with severity (Fig. 2), there was no significant association between long-term control of AD symptoms and provider type.

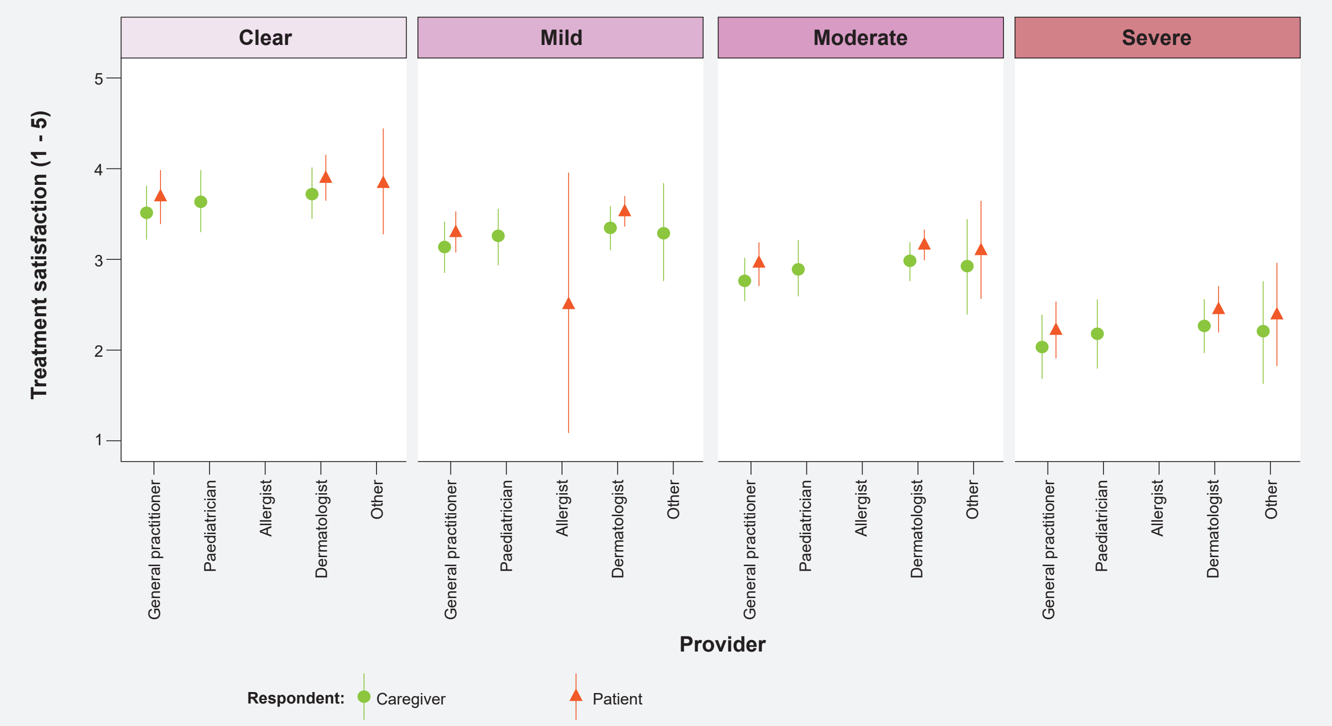

Figure 1 – Predicted mean satisfaction with AD treatments (1 = least satisfied to 5 = most satisfied) stratified by respondent type, provider type, and severity, adjusted for patient age as reported by patients and caregivers in Portugal. Treatment satisfaction score is shown separately for caregiver reported (circles) and patient reported (triangles). Whiskers represent 95% confidence intervals.

Type of specialist care

Respondents were most likely to consult with a dermatologist for AD care (74% of adults, 55% of caregivers) or a family physician (24% of adults, 15% of caregivers). Less than 0.5% of Portuguese AD patients consulted with an allergist. Respondents seeing dermatologists reported higher satisfaction than those seeing other providers (p = 0.01) but no difference in long-term control of symptoms (p = 0.85) when controlling for severity.

Burden of disease and quality of life

Portuguese adult patients scored 0.86/1.00 on the EQ-5D which measures burden of disease where 0 = death to 1 = perfect health. This was higher compared to normal values for Portuguese adults (0.76/1.00).[10] By translation, this score indicates that Portuguese adult patients are willing to trade off 14% of their remaining lifespan to be restored to perfect health. This indicates that AD still poses a burden to those affected with the disease. Data are not reported for this subpopulation since the EQ-5D does not have a version available for caregivers. The average health-related quality of life score identified by the EQ-VAS in adult Portuguese patients was 73/100.

Financial impact

Patients and caregivers in Portugal reported significant financial impact due to AD. Nearly 80% of patients and caregivers reported using savings, borrowing money, and/or reducing spending to cover AD-related costs. In particular, almost 46% of Portuguese respondents report spending less on non-essentials to pay for AD-related expenses (Table 1). Financial worry in Portugal was strongly positively correlated with AD severity (Spearman's ρ = 0.26, $p < 0.001$).

DISCUSSION

Challenges associated with AD management in Portugal are common especially for patient-centered experiences such as treatment satisfaction, shared decision-making, financial impact, and long-term symptom control. Overall, while Portuguese patients are moderately satisfied with their AD treatment, those with severe AD (10.3%) had the lowest treatment satisfaction. Moreover, higher satisfaction was associated with care provided by dermatologists. Even though there are only 4.3 dermatologists per 100 000 individuals in Portugal, the majority of patients in this study had medical appointments with dermatologists (65.2%). Increasing access to dermatologists, more education efforts, and access to innovative treatments for those with more

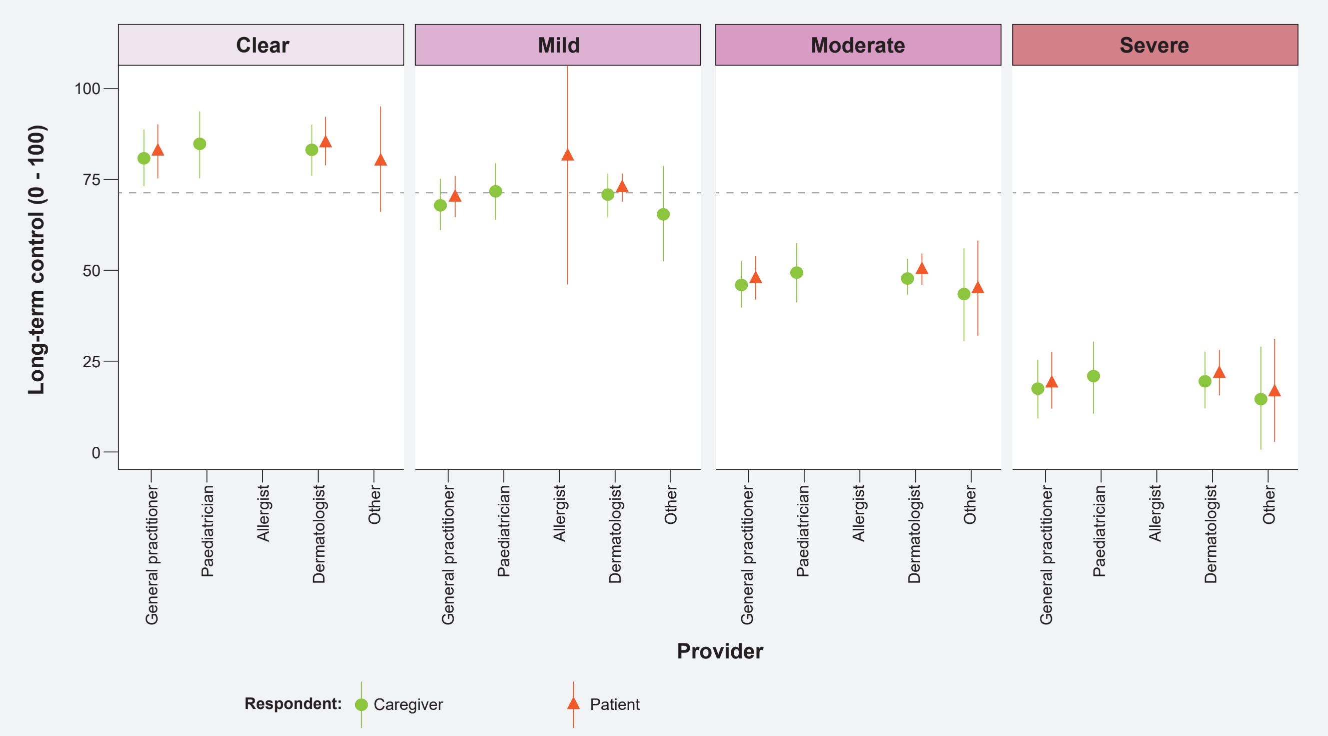

Figure 2 – Predicted mean long-term control (0 - 100) using the rescaled AD Control Tool stratified by respondent type, provider type, and severity, adjusted for patient age. Scores below 70.8 indicate poor control. Long-term control score is shown separately for caregiver reported (circles) and patient reported (triangles) results. Whiskers represent 95% confidence intervals.

severe AD may help improve treatment satisfaction rates and improve overall AD management. Solutions to address the lack of access to providers could include increasing education and training efforts (e.g., using evidence-based clinical practice guidelines on AD[11]) for family physicians in order to add them into the pool of providers that may successfully treat AD.

Shared decision-making is not a common practice in Portugal (66% of adults and 61% of caregivers not being asked about their priorities during the most recent medical visit). Increased efforts to train providers to engage in shared decision-making with patients and caregivers should incorporate patient-centered care practices that encourage participation. This may help increase the number of patients engaging in their own care, increase adherence to treatment, and improve health outcomes. Similarly, most patients and caregivers indicated that they had not been offered any training to address AD. A minority of respondents (6% of adults and 2% of caregivers) said their provider suggested that they attend an AD training program. However, current practice often recommends educational programs for more challenging cases of AD. New initiatives to increase the number of training programs such as eczema schools and similar educational programs that are already being organized, will allow patients and caregivers the opportunity to be more educated on their condition and manage symptoms more effectively.

Considerable financial impact was seen in adult patients and caregivers resulting from AD. An overwhelming majority of adult patients and caregivers (80%) reported that they used savings, borrowed money, or reduced their spending to cover AD-related costs. Increasing financial concern was significantly associated with the severity of AD. As a result, this financial burden may significantly affect the overall financial health of patients or caregivers. This underscores the importance of quickly and effectively providing access to effective and safe treatments, and optimally managing symptoms early in order to prevent disease progression and significant unnecessary long-term spending by patients or caregivers.

In Portugal, access to medical professionals and pharmaceuticals occurs predominantly through the national health service (SNS) which provides universal coverage for its citizens. Patients can access healthcare services, including consultations with dermatologists or other specialists through public hospitals, health centers, or clinics affiliated with the SNS. Pharmaceutical access is facilitated through pharmacies where prescribed medications are often subsidized or partially covered by the SNS depending on the patient's eligibility and the specific medication. While private healthcare options also exist in Portugal, the majority of the population relies on the national health service for their healthcare needs. Health policy decisions that help lower AD-related costs which may not be covered by healthcare systems or identifying novel payment mechanisms for individuals with moderate to severe AD could help alter the financial burden patients and caregivers face. Larger policy decisions that reduce healthcare costs to the patient should be considered within the healthcare system.

Portuguese respondents with moderate or severe AD (53%) did not have adequate control of symptoms compared to those with clear or mild AD (47%). This underscores the need to focus on and address the root cause of uncontrolled symptoms for those with more severe AD. Health-related quality of life for adults with AD (73/100) was lower compared to average adult scores for the whole country (75/100) which suggests an area of opportunity for improvement. Additional research into lifespan trade-off data may help identify best practices or how to better manage AD in the population.

The limitations of this study include recruitment only via online messaging through AD communities. As a result, participants were potentially more likely to be active in these communities and experiencing more impact from AD than others. Patients who take initiative to join these organizations may also be more informed about AD care in general. As this was a cross-sectional study, cause and effect relationships could not be evaluated. Lastly, *de novo* questions did not go through formal validity testing but were framed in simplistic language or yes/no answer choices. Future research should identify what treatments patients are taking and their association with patient-centered attributes such as symptom control and treatment satisfaction.

CONCLUSION

Our results demonstrate that Portuguese patients with AD and caregivers experience financial burden, lower health-related quality of life, higher disease burden, and treatment satisfaction issues. These factors often deteriorate as AD severity increases. Providers, researchers, and policies should focus on addressing patient-centered concerns for individuals suffering from AD in order to improve care and health outcomes. This includes more efforts to train clinicians and incorporate evidence-based clinical guidelines into practice, increasing awareness of eczema schools or educational programs for patients, approving safe and effective treatments, and developing policy decisions to reduce the cost of care. Future research should examine how adequate treatment or psychodermatological approaches could improve health outcomes[12] and how psychosocial factors impact AD.

AUTHOR CONTRIBUTIONS

MT, FM, JC: Study design, drafting, critical review and approval of the manuscript.

AS, KC: Study design, data analysis, drafting, critical review and approval of the manuscript.

PROTECTION OF HUMANS AND ANIMALS

The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in 2013.

DATA CONFIDENTIALITY

The authors declare having followed the protocols in use at their working center regarding patients' data publication.

COMPETING INTERESTS

KC, MT, and FM are employees of Global Parents for Eczema Research, which has received funding in the past from AbbVie, Amgen, Eli Lilly, Incyte, Galderma, Sanofi Regeneron, and LEO Pharma.

AS has received consultant fees from Global Parents for Eczema Research.

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REFERENCES

1. Barbarot S, Auziere S, Gadkari A, Girolomoni G, Puig L, Simpson D, et al. Epidemiology of atopic dermatitis in adults: results from an international survey. Allergy. 2018;73:1284-93.
2. Coelho P, Alpalhão M, Victorino G, Camilo J, Cardoso C, Maia Silva J. Understanding the impact of atopic dermatitis in Portuguese patients: results from an analytical observational study. Value Health. 2022;25:S232.
3. Carvalho D, Aguiar P, Mendes-Bastos P, Palma-Carlos A, Freitas J, Ferrinho P. Quality of life and characterization of patients with atopic dermatitis in Portugal: the QUADEP study. J Investig Allergol Clin Immunol. 2020;30:430-8.
4. Capozza K, Funk M, Hering M, Lang J, Merhand S, Manion R, et al. Patients' and caregivers' experiences with atopic dermatitis-related burden, medical care, and treatments in 8 countries. J Allergy Clin Immunol Pract. 2023;11:264-73.
5. Torres T, Gonçalo M, Paiva-Lopes M, Claro C, Varela P, Silva J, et al. Atopic dermatitis: improving patient access to health care in dermatology. Port J Dermatol and Venereol. 2023;81:1-8.

6. Carvalho D, Aguiar P, Ferrinho P, Mendes-Bastos P, Palma-Carlos A. Eczema and urticaria in the adult population in Portugal: a prevalence study. Actas Dermosifiliogr. 2019;110:744-51.
7. Eyerich K, Gooderham M, Silvestre J, Shumack S, Mendes-Bastos P, Aoki V, et al. Real-world clinical, psychosocial and economic burden of atopic dermatitis: results from a multicountry study. J Eur Acad Dermatol Venereol. 2023;00:1-14.
8. Pariser D, Simpson E, Gadkari A, Bieber T, Margolis D, Brown M, et al. Evaluating patient-perceived control of atopic dermatitis: design, validation, and scoring of the Atopic Dermatitis Control Tool (ADCT). Curr Med Res Opin. 2019;36:367-76.
9. EuroQol Group. EuroQol-a new facility for the measurement of health-related quality of life. Health Policy. 1990;16:199-208.
10. Ferreira L, Ferreira P, Pereira L, Oppe M. EQ-5D Portuguese population norms. Qual Life Res. 2014;23:425-30.
11. Torres T, Gonçalo M, Paiva-Lopes M, Claro C, Ramos L, Selores M, et al. Portuguese recommendations for the treatment of atopic dermatitis with biologic therapy and JAK inhibitors in adult patients. Drugs Context. 2021;10:2021-9-5.
12. Hartono SP, Chatrath S, Aktas ON, Kubala SA, Capozza K, Myles IA, et al. Interventions for anxiety and depression in patients with atopic dermatitis: a systematic review and meta-analysis. Sci Rep. 2024;14:8844.