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https://doi.org/10.1007/s13555-025-01417-y

Dermatol Ther (Heidelb) (2025) 15:1543–1553
https://doi.org/10.1007/s13555-025-01417-y

BRIEF REPORT

Comparison of Dermatology Life Quality Index Scores in Adults and Adolescents with Alopecia Areata

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Received: February 17, 2025 / Accepted: April 8, 2025 / Published online: April 24, 2025

ABSTRACT

Introduction: This study assessed Dermatology Life Quality Index (DLQI) scores of patients with alopecia areata (AA) and compared scores between adults and adolescents.

Methods: This was a retrospective chart review in France, Germany, Spain, and the UK. Patients with ≥ 50% scalp hair loss (SHL) due to AA and a DLQI score recorded at their index date (first date of ≥ 50% SHL) were included. The DLQI (scale 0–30; higher scores indicate greater impact) assesses the impact of AA on health-related quality of life (QOL). Multivariable linear regression was used to examine the effect of age on DLQI score, adjusting for covariates. Modified Poisson regression analysis was used to estimate relative risks (RRs) between age groups and DLQI categories (none to moderate effect, very large effect, and extremely large effect), adjusting for covariates, including baseline Severity of Alopecia Tool (SALT) score.

Results: Overall, 335 patients were included (249 adults, 86 adolescents). At index, adults had a higher mean (SD) SALT score than adolescents (63.7 [15.5] vs 60.4 [12.8]), whereas mean (SD) DLQI scores were higher in adolescents than adults (22.1 [5.3] vs 18.2 [7.5]). Most patients (84%) had DLQI scores indicating a very large or extremely large impact on their lives; this was more pronounced in adolescents than adults (98% vs 80%). In the multilinear model, adolescents had significantly higher DLQI scores than adults (β = 3.51; $P < 0.001$), indicating a 3.51-point increase in DLQI score associated with being an adolescent. The RR (95% CI) of a DLQI score indicating a very large effect (1.28 [1.07–1.53]) or extremely large effect (1.40 [1.21–1.61]) relative to no or moderate effect was significantly higher for adolescents vs adults.

Conclusion: This study demonstrates that, at the time of experiencing ≥ 50% SHL due to AA, both adults and adolescents reported significant impacts on their QOL, with a higher impact on adolescents.

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Keywords: Adolescents; Adults; Alopecia areata; Dermatology Life Quality Index; Hair loss; Quality of life

Key Summary Points

Why carry out this study?

Patients with alopecia areata (AA) often report anxiety, depression, embarrassment, or low self-esteem and may avoid social settings because of fear of judgment or unwanted attention.

Although hair loss due to AA can negatively affect quality of life among people of all ages, adolescents may be particularly susceptible to its psychosocial impacts.

This study examined the impact of age on the quality of life of patients at the time of experiencing ≥ 50% scalp hair loss due to AA in a European cohort from 2015 to 2019 using the Dermatology Life Quality Index (DLQI).

What was learned from the study?

AA had a substantial impact on quality of life among both adults and adolescents with ≥ 50% scalp hair loss, with approximately 80% of adults and 98% of adolescent having DLQI scores indicating that AA had a very large or an extremely large effect on their quality of life.

This study demonstrates the substantial impact of AA on quality of life among adults and adolescents experiencing their first episode of ≥ 50% scalp hair loss, as measured by the DLQI.

The findings underscore the need for effective treatments for both adults and adolescents with AA.

INTRODUCTION

Alopecia areata (AA) is an autoimmune disease characterized by nonscarring hair loss of the scalp, face, and/or body that has an estimated global prevalence of 0.58–2% [1–4]. Clinical presentation of AA can range from small patches to complete loss of scalp hair (alopecia totalis) or complete loss of scalp, face, and body hair (alopecia universalis) [5, 6]. AA has an unpredictable and often relapsing disease course [7]. Severity of AA is not limited to the extent and/or location of hair loss, as hair loss due to AA is associated with significant psychosocial impacts, often leading to impaired quality of life [8, 9]. Individuals with AA may report anxiety, depression, embarrassment, or low self-esteem and may avoid social settings because of fear of judgment or unwanted attention [9, 10]. Although hair loss due to AA can negatively affect quality of life among people of all ages, adolescents may be particularly susceptible to its psychosocial impacts [11]. While there are many studies demonstrating the detrimental psychosocial effects of AA, limited information is available on how quality of life differs between adults and adolescents with AA, particularly among those with AA with ≥ 50% scalp hair loss.

Traditional, off-label treatments for AA have included topical, intralesional, or systemic corticosteroids and other immunosuppressants, which have limited tolerability and efficacy for severe disease. In 2022 and 2024, the JAK1/2 inhibitors baricitinib and deuruxolitinib, respectively, were approved to treat adults with severe AA, and in 2023, the JAK3/TEC family kinase inhibitor ritlecitinib was approved to treat adults and adolescents with severe AA [12–14].

The Dermatology Life Quality Index (DLQI) is the most widely used tool to assess the impact of dermatologic conditions on health-related quality of life [15, 16]. As a self-administered questionnaire, the DLQI captures emotional, psychological, and functional dimensions of the impact of skin disease on quality of life over the last 7 days. Although various studies have used the DLQI to evaluate AA burden [17], research to date has not yet evaluated whether DLQI scores differ between adults and adolescents with AA. This study aimed to examine the impact of age (adult vs adolescent) on the quality of life of patients with ≥ 50% scalp hair loss due to AA in a European cohort from 2015 to 2019 using the DLQI.

METHODS

Data Source

The Alopecia Areata in a Global Noninterventional Observational Cohort (ADAAGIO) study was a retrospective medical record review conducted in France, Germany, Spain, and the UK [18]. Medical record review was led by dermatologists experienced in managing patients with AA. The study was subjected to local ethics committee reviews for exemption (in France and the UK) or approval (in Spain and Germany) per local data privacy requirements on the basis that all data collected were fully anonymized prior to analysis.

Patient Population

Patients eligible for inclusion in ADAAGIO were required to meet the following criteria: diagnosis of AA with ≥ 50% scalp hair loss, aged ≥ 12 years at index, and ≥ 6 months of available post-index follow-up. Patients also needed to be receiving ongoing treatment for AA at index, or, if treatment naive, initiating new treatment for AA within 60 days post index. Furthermore, all patients were required to have ≥ 1 post-index clinic visit during which percent scalp hair loss was recorded. Patients were excluded if they had other types of alopecia, other diseases that can cause hair loss, or other scalp diseases that could interfere with assessments of hair loss or regrowth.

The index date was defined as the first observed date of de novo or progression to ≥ 50% scalp hair loss occurring between January 1, 2015, and December 31, 2019. This cross-sectional analysis of the ADAAGIO study included patients who had a DLQI score recorded at their index date.

Outcomes

The DLQI is a questionnaire consisting of 10 questions regarding symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment as dimensions of life [15]. Each item is scored on a scale of 0–3 points, and scores are added for a total DLQI score of 0–30 points. Higher scores indicate greater impact of disease on quality of life. DLQI scores of 0–1 indicate no effect at all on quality of life, scores of 2–5 indicate a small effect, scores of 6–10 indicate a moderate effect, scores of 11–20 indicate a very large effect, and scores of 21–30 indicate an extremely large effect [19].

Statistical Analysis

Analyses were stratified by age group at index: adults (aged ≥ 18 years) and adolescents (aged 12–17 years). Patient demographics and clinical characteristics were described using descriptive statistics. Standardized mean differences were calculated to assess the balance of baseline characteristics between the two age groups, with a standardized mean difference of <0.1 indicating good balance.

To assess the effect of age group on DLQI score as a continuous variable, multivariable linear regression was conducted, with adjustment for a pre-specified list of covariates selected a priori based on primary literature and expert knowledge. Covariates included country, sex, race, AA type, Severity of Alopecia Tool (SALT) score at index, scalp hair loss ≥ 50% at diagnosis, eyebrow involvement, eyelash involvement, index year, presence of concomitant dermatologic conditions, presence of comorbid anxiety, and presence of comorbid depression. Regression coefficients (β, standard errors [SEs], and *P* values) were reported.

To assess the effect of age group on DLQI category, DLQI score was discretized into three mutually exclusive categories (none to moderate effect [DLQI score 0–10], very large effect [DLQI score 11–20], and extremely large effect [DLQI score 21–30]), with the none to moderate effect category serving as the reference group. Relative risks (RRs) and 95% CI between age group and DLQI category were estimated using modified Poisson regression analyses with a log link and robust SEs. The first model compared the RR of being in the very large effect category vs the none to moderate effect category, and the second model compared the RR of being in the

extremely large effect category vs the none to moderate effect category. Both models were adjusted for the covariates described above. Two-sided P values < 0.05 were considered statistically significant.

RESULTS

Patient Characteristics

A total of 335 patients (249 adults and 86 adolescents) had DLQI scores at index and were included in the analysis (Table 1). A higher proportion of adolescents indexed into the study in 2017 or earlier (74.4%) compared with adults (50.6%). The mean age (SD) at the index date was 34.1 (11.8) years for adults and 15.0 (1.5) years for adolescents, and the majority of patients in each group were female (56.2% of adults and 74.4% of adolescents). Adult patients had more extensive hair loss at index than adolescents: mean (SD) SALT scores were 63.7 (15.5) in adults and 60.4 (12.8) in adolescents, and 20.9% of adults had alopecia totalis/alopecia universalis vs 11.6% of adolescents. Anxiety was present/ongoing at the index date in 20.9% of adults and 25.6% of adolescents; depression was present/ongoing in 12.4% of adults and 3.5% of adolescents.

DLQI Scores at Index

As previously reported, at index, DLQI scores were higher in adolescents (mean [SD] 22.1 [5.3], median [interquartile range] 24.0 [8.0]) than adults (mean [SD] 18.2 [7.5], median [interquartile range] 19.0 [11.0]) [18]. Overall, most patients (84.5%) had a DLQI score at index indicating a very large or extremely large effect on the patient's life (Fig. 1). This was especially pronounced among adolescents, with 97.7% reporting DLQI scores indicating a very large or an extremely large effect, and only 2 patients (2.3%) with a DLQI score indicating a moderate effect. No adolescents had DLQI scores indicating no effect or a small effect. The majority of adolescents (60.5%) had DLQI scores indicating an extremely large effect, while among adults, 39.8% had DLQI scores indicating an extremely large effect and 40.2% had DLQI scores indicating a very large effect [18].

Impact of Age Group on DLQI Score

In the multivariable linear regression model, adolescents had significantly higher DLQI scores compared with adults ($\beta = 3.51$; SE 0.818; $P < 0.001$), indicating that being an adolescent was associated with a mean increase of 3.51 points in the DLQI score, when variables other than age group were held constant (Table 2). In the multivariable Poisson regression model, the RR of reporting a DLQI score indicating a very large effect (DLQI score 11–20) relative to reporting no effect to a moderate effect (DLQI score 0–10) was significantly higher for adolescents vs adults (RR 1.28; 95% CI 1.07–1.53), when other variables were held constant (Fig. 2). Similarly, the RR of reporting a DLQI score indicating an extremely large effect (DLQI score 21–30) relative to reporting no effect to a moderate effect (DLQI score 0–10) was also significantly higher for adolescents vs adults (RR 1.40; 95% CI 1.21–1.61), when other variables were held constant.

DISCUSSION

These results highlight the substantial impact of AA on quality of life in adults and adolescents at the time of experiencing ≥ 50% scalp hair loss. Additionally, these results show an especially large impact on adolescents. Nearly 80% of adults had DLQI scores indicating that AA had a very large or an extremely large effect on their quality of life, and this was true for nearly all adolescents (98%). Although the impact of AA involving ≥ 50% scalp hair loss on both adults and adolescents was striking, AA in adolescence (age 12–17 years) was significantly associated with higher DLQI scores, even after adjustment for potential confounding factors such as SALT scores, comorbid dermatologic conditions, and mental health conditions. Although item-level scores were not available, higher DLQI scores among adolescents may potentially be explained

Table 1 Patient demographics and clinical characteristics

	Overall ($N = 335$)	Age groups		
		Adults ($n = 249$)	Adolescents ($n = 86$)	Difference*
Country, *n* (%)				
France	23 (6.9)	23 (9.2)	0 (0)	0.74
Germany	92 (27.5)	75 (30.1)	17 (19.8)	
Spain	86 (25.7)	71 (28.5)	15 (17.4)	
UK	134 (40.0)	80 (32.1)	54 (62.8)	
Year of study index date, *n* (%)				
2015	48 (14.3)	26 (10.4)	22 (25.6)	0.60
2016	55 (16.4)	38 (15.3)	17 (19.8)	
2017	87 (26.0)	62 (24.9)	25 (29.1)	
2018	79 (23.6)	70 (28.1)	9 (10.5)	
2019	66 (19.7)	53 (21.3)	13 (15.1)	
Age at study index date, years				
Mean (SD)	29.2 (13.2)	34.1 (11.8)	15.0 (1.5)	2.30
Median (IQR)	27.0 (21.0)	31.0 (16.0)	15.0 (2.0)	
Range	12.0–75.0	18.0–75.0	12.0–17.0	
Sex, *n* (%)				
Female	204 (60.9)	140 (56.2)	64 (74.4)	0.39
Male	131 (39.1)	109 (43.8)	22 (25.6)	
Race/ethnicity, *n* (%)				
African/Black	23 (6.9)	17 (6.8)	6 (7.0)	0.37
East Asian	21 (6.3)	16 (6.4)	5 (5.8)	
South Asian	16 (4.8)	11 (4.4)	5 (5.8)	
Middle Eastern	16 (4.8)	13 (5.2)	3 (3.5)	
Multi-race/ethnicity	16 (4.8)	10 (4.0)	6 (7.0)	
White/Caucasian	237 (70.7)	181 (72.7)	56 (65.1)	
Other/unknown	6 (1.8)	1 (0.4)	5 (5.8)	
Patients presenting with ≥ 50% SHL at index, *n* (%)				
No (diagnosis date occurred before index date)	99 (29.6)	78 (31.3)	21 (24.4)	0.15
Yes (diagnosis date = index date)	236 (70.4)	171 (68.7)	65 (75.6)	

Table 1 continued

	Overall ($N = 335$)	Age groups		
		Adults ($n = 249$)	Adolescents ($n = 86$)	Difference*
AA type at index, *n* (%)				
Alopecia totalis	39 (11.6)	31 (12.4)	8 (9.3)	0.30
Alopecia universalis	23 (6.9)	21 (8.4)	2 (2.3)	
Patchy alopecia	273 (81.5)	197 (79.1)	76 (88.4)	
SALT score ascertainment method, *n* (%)				
Physician estimation	116 (34.6)	62 (24.9)	54 (62.9)	0.83
SALT calculation	219 (65.4)	187 (75.1)	32 (37.2)	
SALT score at index, *n* (%)				
Mean (SD)	62.9 (14.9)	63.7 (15.5)	60.4 (12.8)	0.23
Median (IQR)	56.0 (16.0)	56.0 (18.0)	55.5 (8.8)	
Range	50.0–100.0	50.0–100.0	50.0–100.0	
Other sites of hair loss/involvement at index, *n* (%)				
Eyebrows	141 (42.1)	106 (42.6)	35 (40.7)	0.04
Eyelashes	110 (32.8)	82 (32.9)	28 (32.6)	0.01
Beard (males only)	47 (35.9)	41 (37.6)	6 (27.3)	0.22
Extremities	31 (9.3)	24 (9.6)	7 (8.1)	0.05
Torso	35 (10.4)	33 (13.3)	2 (2.3)	0.42
Pubic areas	40 (11.9)	34 (13.7)	6 (7.0)	0.22
No body hair loss	219 (65.4)	159 (63.9)	60 (70.8)	0.13
Nail involvement	42 (12.5)	30 (12.0)	12 (14.0)	0.06
Comorbidities present/ongoing at index, *n* (%)				
Anxiety	74 (22.1)	52 (20.9)	22 (25.6)	0.11
Obsessive–compulsive disorder	7 (2.1)	6 (2.4)	1 (1.2)	0.09
Sleep disorder	10 (3.0)	10 (4.0)	0 (0)	0.29
Depression	34 (10.1)	31 (12.4)	3 (3.5)	0.34
Bipolar disorder	2 (0.6)	2 (0.8)	0 (0)	0.13
Alexithymia	2 (0.6)	2 (0.8)	0 (0)	0.13
Schizophrenia	1 (0.3)	1 (0.4)	0 (0)	0.09
Attention deficit disorder	2 (0.6)	2 (0.8)	0 (0)	0.13
Personality disorder	2 (0.6)	2 (0.8)	0 (0)	0.13
Atopic dermatitis†	28 (8.5)	23 (9.5)	5 (5.8)	0.14

Table 1 continued

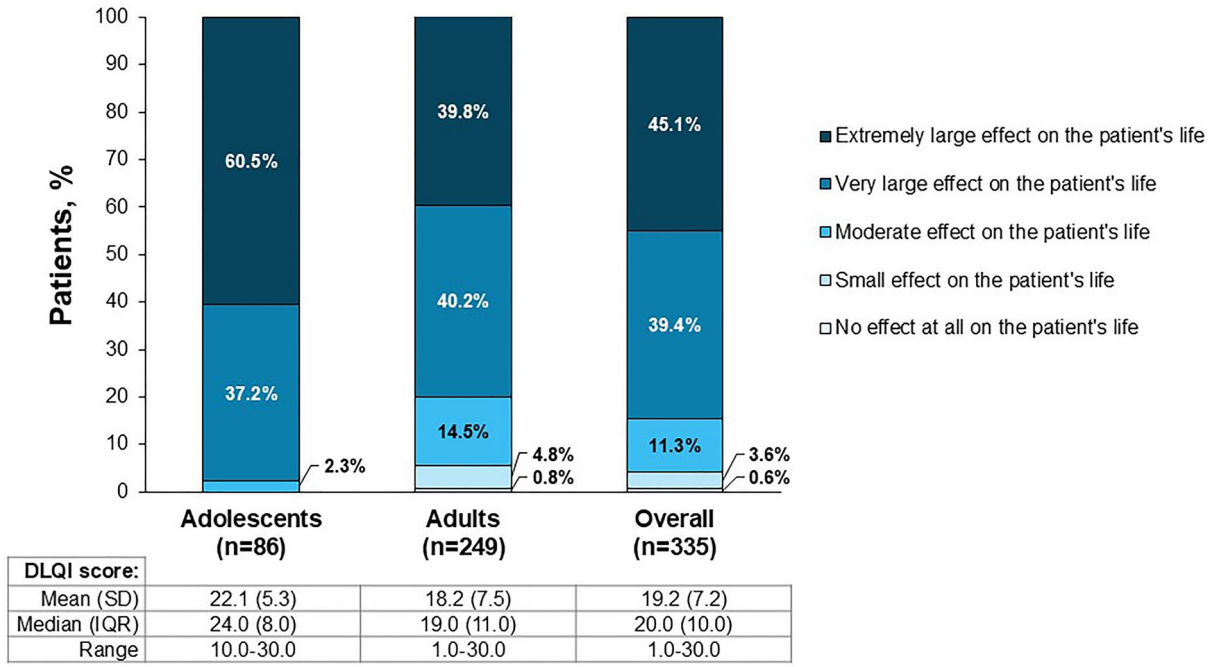
	Overall ($N = 335$)	Age groups		
		Adults ($n = 249$)	Adolescents ($n = 86$)	Difference*
Allergic rhinitis[†]	24 (7.3)	19 (7.9)	5 (5.8)	0.08
Asthma[†]	12 (3.7)	10 (4.1)	2 (2.3)	0.10
Other unspecified atopic disorder[†]	4 (1.2)	1 (0.4)	3 (3.5)	0.22
Any dermatologic condition[†,‡]	43 (12.8)	36 (14.5)	7 (8.1)	0.21

AA alopecia areata, *IQR* interquartile range, *SALT* Severity of Alopecia Tool, *SHL* scalp hair loss

*Standardized mean difference

[†]Unknown in 7 patients; proportion out of patients with non-missing data

[‡]Dermatologic conditions included atopic dermatitis, psoriasis, systemic lupus erythematosus, and vitiligo



DLQI score:	Adolescents (n=86)	Adults (n=249)	Overall (n=335)
Mean (SD)	22.1 (5.3)	18.2 (7.5)	19.2 (7.2)
Median (IQR)	24.0 (8.0)	19.0 (11.0)	20.0 (10.0)
Range	10.0-30.0	1.0-30.0	1.0-30.0

Fig. 1 DLQI score categories at index: scores 0–1 = no effect at all, scores 2–5 = small effect, scores 6–10 = moderate effect, scores 11–20 = very large effect, and scores 21–30 = extremely large effect. *DLQI* Dermatology Life Quality Index

by specific domains that may be more important to adolescents than adults, such as social isolation. In a prior study, children aged 4–16 years with AA responding to the DLQI reported the most severe impacts on their choice of clothing and feelings of self-consciousness [20]. Emotional distress may also resonate more strongly with adolescents than adults given that adolescence is a time when people become more aware of their own feelings and experience significant fluctuations in emotions. Furthermore, it is possible that given their younger age, the adolescents in this analysis had a shorter disease duration than the adults and therefore less time to adjust to the emotional and psychological aspects of the disease.

Prior research on the impact of AA on the quality of life of adolescents is limited; to our

Table 2 Crude and adjusted linear regression results: impact of age group on DLQI scores

Model	Predictor	Estimate (β)	Standard error	*P*
Crude	Age group (adolescents vs adults)	3.861	0.872	< 0.001
Adjusted*	Age group (adolescents vs adults)	3.510	0.818	< 0.001

DLQI Dermatology Life Quality Index

*Adjusted for country, sex, race, alopecia areata type, Severity of Alopecia Tool score at index, scalp hair loss ≥ 50% at diagnosis, eyebrow involvement, eyelash involvement, index year, concomitant dermatologic conditions, comorbid anxiety, and comorbid depression

knowledge, no studies have focused on this age group and on patients experiencing ≥ 50% scalp hair loss. A previous survey of patients with AA reported mean (SD) DLQI scores of 7.7 (7.4) for adults and 6.3 (5.9) for children aged 4–16 years [20], with 17.6% of children reporting DLQI scores indicating a very large to an extremely large impact and 31.0% of adults reporting DLQI scores indicating a very large to an extremely large impact. Additional studies of patients with AA have also reported lower DLQI scores than those in our study, including a meta-analysis describing a mean DLQI score of 6.3 for adults [17] and a cross-sectional study reporting a mean DLQI score of 6.1 in adults (21.2% reporting scores indicating a very large or an extremely large effect) and 2.25 in children (6.7% reporting a very large or an extremely large effect) [21]. The lower DLQI scores reported in these studies compared with those in our study are likely due in part to differences in the patient populations, as well as varying degrees of severity. For example, in the cross-sectional study, 85% of patients had < 25% scalp hair loss [21], in contrast to our study of patients with higher degrees of scalp hair loss (≥ 50%). However, a study of patients with AA in Japan also found lower

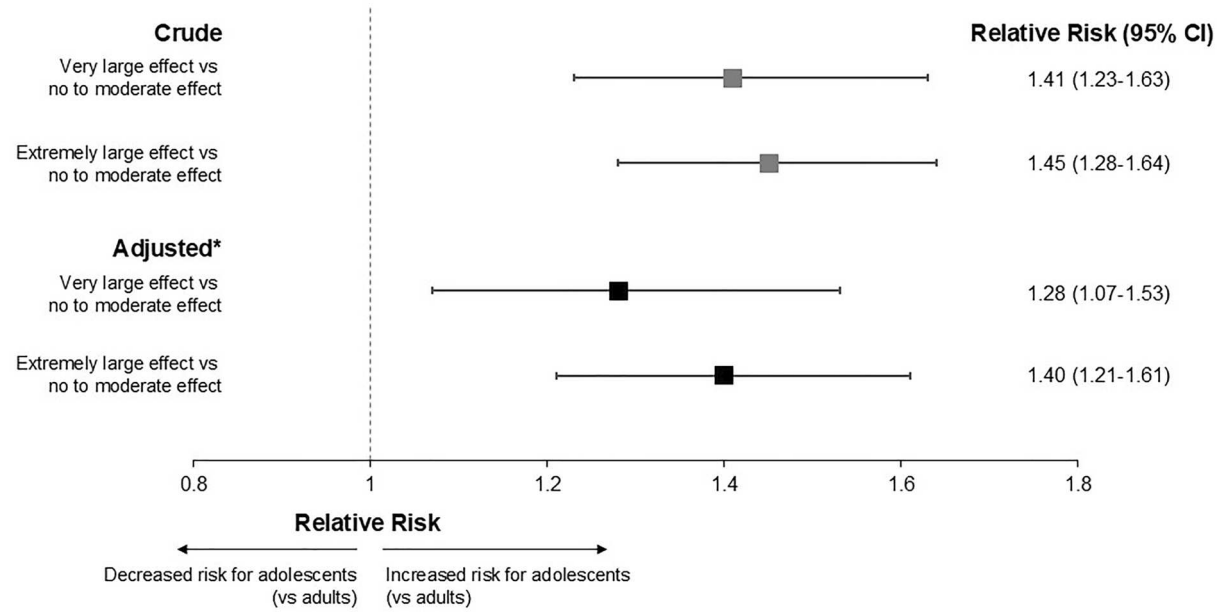


Fig. 2 Impact of age group on DLQI score categories. *Adjusted for country, sex, race, alopecia areata type, Severity of Alopecia Tool score at index, scalp hair loss ≥ 50% at diagnosis, eyebrow involvement, eyelash involvement, index year, concomitant dermatologic conditions, comorbid anxiety, and comorbid depression. *DLQI* Dermatology Life Quality Index

DLQI scores, including among patients with ≥ 50% scalp hair loss; in this study, only 30% of the 33 patients with ≥ 50% scalp hair loss had DLQI scores indicating a very or an extremely large effect [22]. In our study, DLQI scores were captured at the moment of patients' first episode of ≥ 50% scalp hair loss, which likely contributed to the higher scores observed in our study compared with the prior study in which patients may have had time to adapt to the impacts of more extensive hair loss.

This study has some limitations. The cross-sectional nature of the data limits the ability to infer causal relationships between age and quality of life and between AA and quality of life; factors outside of age and/or AA may have influenced how patients responded to the DLQI questionnaire. The absence of longitudinal data limits the understanding of how DLQI scores evolve over time in relation to AA, which is particularly important in a disease such as AA that may be subject to spontaneous remission. Additionally, the DLQI has not been validated for AA, and it explicitly refers to skin in all its items, which may bias responses toward lower impact scores. Further, caution should be exercised when interpreting the Poisson regression results because of imprecision of the estimates, as evidenced by wide CIs. The imprecision arises from sparse data in the reference category, leading to unstable RR estimates and limiting the certainty of the association observed. The study used a convenience sample, which may limit the generalizability of the findings. The inclusion criteria for patients receiving continued treatment for AA or initiating new treatment may also contribute to the higher DLQI scores (worse quality of life) observed in this study, as selecting for patients seeking out treatment may also limit generalizability; DLQIs may not have been administered routinely and potentially administered more often to patients who had clearly impaired quality of life, leading to an apparently more severe effect. Finally, these data were collected between 2015 and 2019, prior to the approval of new treatments (baricitinib, ritlecitinib, and deuruxolitinib) shown to improve hair regrowth, which have the potential to improve quality of life in patients with severe AA.

CONCLUSIONS

This study demonstrates the substantial impact of AA on quality of life among adults and adolescents experiencing their first episode of ≥ 50% scalp hair loss, as measured by the DLQI. The impact of AA on quality of life was high for nearly all adolescents. Adolescents are at a critical stage of identity development and social interactions and therefore may be especially susceptible to the appearance-related concerns and stigma associated with AA. Further studies are needed to assess changes in DLQI score over time and in response to treatment and its correlation with extent of hair loss. The findings underscore the need for effective treatments for both adults and adolescents with AA.

ACKNOWLEDGEMENTS

We thank the participants of this study.

Medical Writing/Editorial Assistance. Medical writing support for the development of this publication was provided by Ellen Mercado, PhD, of Nucleus Global and was funded by Pfizer Inc.

Author Contribution. Kent A. Hanson, Sergio Vañó-Galván, Andrew Messenger, Helen Tran, Lynne Napatalung, Keith L. Davis, Lizzi Esterberg and Ernest H. Law contributed to the concept and design of the study, data interpretation, and drafting the manuscript, and provided final approval of the submitted manuscript. Statistical analyses were performed by Keith L. Davis and Lizzi Esterberg.

Funding. This study was sponsored by Pfizer Inc. Fees for the journal's Rapid Service was funded by Pfizer Inc.

Data Availability. The datasets generated during and/or analyzed during the current study are not publicly available due to ethics requirements protecting the privacy of individuals whose medical records were reviewed for the study.

Declarations

Conflict of interest. This study was funded by Pfizer Inc. Ernest H. Law, Helen Tran, and Lynne Napatalung report employment with and stock ownership in Pfizer Inc. Kent A. Hanson served as a paid consultant to Pfizer during the period in which the work for this manuscript was conducted; the author is no longer affiliated with the company. Keith L. Davis and Lizzi Esterberg report employment with RTI Health Solutions, which received contract research funding from Pfizer Inc. for the conduct of this study. Andrew Messenger and Sergio Vañó-Galván report consultancy fees from Pfizer Inc. in relation to the conduct of this study.

Ethical approval. The study was subjected to ethics review and approval (or exemption, as applicable) based on local, country-specific requirements. In the UK, based on the National Health Service's Health Research Authority (HRA) online decision tool, the study was classified as a service evaluation or clinical/non-financial audit; thus, the study was exempt from research ethics committee review (HRA decision tool certificate of exemption available upon request). In France, based on the retrospective, non-interventional study design in which only fully anonymized data were collected and retained, the study required only attestation of compliance with MR-004 (research methodology 004) to the Commission Nationale Informatique and Libertés. In Germany, the study underwent independent ethics committee (IEC) review (with subsequent approval) with the Ethikkommission der Bayerischen Landesärztekammer, in addition to notification of study conduct to the Ethikkommission der Bayerischen Landesärztekammer. In Spain, IEC review (and subsequent approval) was obtained from Hospital Universitario La Paz, with competent authority notification to Agencia Española de Medicamentos y Productos Sanitarios.

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