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Alopecia Areata: Impact on Patients' Quality of Life and Disease Perception: A Survey-Based Study

Christian VESTERGAARD[1], Daniel DE LA ROSA CARRILLO[2], Randeep MANDLA[3], Anne Grete FRØSTRUP[4], Susanne T. GREN[4], Petri VÄNNI[5], Anna-Kaisa ASIKAINEN[5], Kristian KOFOED[6] and Cato MØRK[7]
[1]Department of Dermatology, Aarhus University Hospital, Aarhus, Denmark, [2]Volvat Medical Centre, Oslo, Norway, [3]Pfizer AS, Oslo, Norway, [4]Pfizer Denmark, Ballerup, Denmark, [5]Nordic Healthcare Group, Espoo, Finland, [6]Roedovre Skin Clinic, Copenhagen, Denmark, and [7]Akershus Dermatology Centre, Lørenskog, Norway

Alopecia areata significantly impacts patients' emotional and psychosocial well-being. This survey investigated patients' perspectives on disease severity and its impact on quality of life. The study evaluated whether disease assessment tools (Severity of Alopecia Tool, Dermatology Life Quality Index, and Patient Unique Stigmatization Holistic tool in dermatology) reflect patients' perceptions of their condition. The study was conducted as an anonymous social media survey in Norway and Denmark. The questionnaire was divided into 3 main sections: (*i*) demographics and disease characteristics; (*ii*) disease severity and QoL measures; and (*iii*) patient perception and psychosocial impact. A total of 360 individuals participated in the survey reporting alopecia areata as mild (15%), moderate (29%), or severe (58%). Some 61% reported alopecia areata to interfere with their daily or weekly activities. All disease assessment tools demonstrated an age-dependent pattern, where scores were highest in the youngest (<30 years) responder group. The relationship between Dermatology Life Quality Index and Severity of Alopecia Tool scores was found to be weak (R-squared = 0.08). Similarly, the correlation between Dermatology Life Quality Index and self-reported disease severity was also weak (R-squared = 0.136). This study demonstrates that there is a clear need for the development of more comprehensive, validated, and patient-centred assessment tools that can accurately reflect the physical, emotional, psychological, and social challenges faced by individuals with alopecia areata.

Key words: alopecia areata; measurement tools; quality of life; dermatology; hair; impact on daily life.

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Corr: Randeep Mandla, Postbox 3, NO-1324 Lysaker, Norway. E-mail: randeep.mandla@pfizer.com

SIGNIFICANCE

This study highlights the personal struggles faced by individuals with alopecia areata, particularly how it impacts their daily lives and well-being. It sheds light on the disconnect between traditional assessment tools and the lived experiences of those affected. The findings emphasize the need for more patient-centred tools that take into account the emotional and psychosocial challenges of alopecia areata in addition to its physical symptoms. This research will contribute to existing studies by offering a deeper understanding of patient perspectives, ultimately improving care and support for individuals coping with this chronic condition.

Alopecia areata (AA) takes a significant emotional and psychological toll on affected individuals (1, 2). The unpredictability of the disease course makes AA particularly challenging to manage. Some patients experience spontaneous hair regrowth, while others endure chronic, relapsing hair loss (1). The psychosocial impact of AA can be significant, as hair is often tied to cultural and societal perceptions of identity, health, beauty, and normalcy (3, 4). Patients with AA frequently report feelings of isolation, depression, anxiety, and decreased self-esteem. As such, understanding how patients perceive their disease and the degree to which AA affects their quality of life (QoL) is critical in providing holistic care.

In clinical practice, disease severity is often measured using the Severity of Alopecia Tool (SALT), which quantifies the extent of scalp hair loss in 4 quadrants of the scalp (5). While SALT offers an objective measure of hair loss, it does not capture the psychosocial and emotional burden of the disease. In contrast, the Dermatology Life Quality Index (DLQI) is a commonly used tool to assess QoL in patients with dermatological conditions, including AA. However, the DLQI is not specifically validated or designed for AA patients, raising concerns about its sensitivity in this population (6).

This patient survey aimed to investigate how patients perceive their disease severity and how AA impacts their daily lives. It also sought to assess whether commonly used measurement tools like SALT and DLQI adequately reflect patient perceptions. By understanding the gaps in current assessment tools, we hope to highlight the need for more comprehensive approaches to evaluating the impact of AA on patients.

MATERIALS AND METHODS

Study design and participants

The study was conducted as an anonymous survey in Norway and Denmark. A link was distributed through social media platforms (Facebook, Instagram, and TikTok), which have been shown to be a suitable method for survey distribution (7). The data collection period spanned from November 2023 to February 2024. Participants were required to be at least 18 years old, and informed consent was obtained prior to completing the survey. The consent included permission to publish results in aggregate form, ensuring anonymity and privacy. The Danish Ethical Committee does not require approval for anonymous, survey-based research that does not involve identifiable human subjects, individual-level data, or biological materials (8). Although similar guidance is provided by the Norwegian Ethical Committee (9), it does not explicitly mention survey-based research. The Norwegian Ethical Committee responded affirmatively (assessment no. #722865) to a query that ethical approval is not required for anonymous surveys. Data privacy impact assessment was conducted to ensure compliance with local regulations.

Survey structure

The survey was divided into 3 main sections:

1. *Demographics and Disease Characteristics:* Participants were asked to provide information regarding their age, gender, disease duration, and AA subtype (AA, AT, AU, or other forms).
2. *Disease Severity and HRQoL Measures:* Patients were instructed to self-report their disease severity using the SALT score and to complete the DLQI questionnaire to assess the impact of AA on their QoL.
3. *Patient Perception and Psychosocial Impact:* The survey included additional questions on participants' subjective perception of disease severity, categorized as mild, moderate, or severe. The Patient Unique Stigmatization Holistic tool in dermatology (PUSH-D) was used to evaluate feelings of stigmatization related to hair loss.

Assessment tools

SALT score: SALT is an objective tool used to quantify the extent of scalp hair loss. Patients were asked to estimate the percentage of hair loss in 4 regions of their scalp (top, left, right, and back). These values were used to calculate a total SALT score, which ranges from 0 (no hair loss) to 100 (complete hair loss) (10). In this study, the SALT score was self-reported, which impacts the interpretation of the results (11).

DLQI: The DLQI is a 10-item questionnaire used to measure the impact of skin conditions on QoL. The DLQI score ranges from 0 (no impact) to 30 (severe impact), with higher scores indicating a greater impact on daily activities, emotional well-being, and social functioning (12). A DLQI score of ≥ 10 is commonly used for defining severe dermatological disease (13).

PUSH-D: This tool assesses the psychosocial impact of stigmatization due to skin conditions. It measures feelings of embarrassment, isolation, and other emotional responses to visible skin or hair changes through 17 questions with the options: "never" (rated 0), "rarely" (1), "sometimes" (2), "often" (3), "very often" (4), and "not applicable" (rated 0) (14). Higher scores are associated with higher stigma.

Data analysis

Descriptive statistics were used to summarize demographic and clinical characteristics of the study population. Univariable linear regression was performed to examine the relationship between SALT scores, DLQI scores, and patient-reported disease perception. Statistical analyses were performed using a Wilcoxon test, *t*-test, and univariable linear regression with Microsoft Excel (Microsoft Corp, Redmond, WA, USA) and R version 4.3.0 for Windows (R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

A total of 360 individuals participated in the survey, with the majority being women (94%) (**Table I**). Among respondents, 15% perceived their disease as mild, 29% as moderate, and 56% as severe, which varied considerably by age group (**Fig. 1**A).

The median age of respondents was 52 years, the median duration of disease since diagnosis was 12 years, and 43% responded they were below 30 years of age at the time of diagnosis. The distribution of AA subtypes was as follows: 53% had patchy AA, 26% had AU, 12% had AT, and 8% reported having other forms of AA (see Table I). Only 57% reported having received any treatment for their disease and merely 28% were receiving treatment when responding to this survey.

The median SALT score was 18.0 (13.5–22.3), the median DLQI score was 7.0 (6.0–8.0), and the median PUSH-D score was 13.0 (11.0–14.0). All scores demonstrated an age-dependent pattern, where the scores were highest in the youngest responder group (<30 years) (Fig. 1B).

Table I. Responder demographic and clinical characteristics

Item	All patients ($N=360$) *n* (%)/Median (CI 95%)
Female sex, *n* (%)	340 (94.4%)
Age, years, median	52.0 (49.0 – 55.0)
Age at diagnosis, years, median	32.0 (30.0 – 35.0)
Time since diagnosis, median	12.0 (10.0 – 14.0)
Received any treatments to AA, *n* (%)	206.0 (57.2%)
Condition, *n* (%)	
Alopecia areata, *n* (%)	191 (53.1%)
Alopecia universalis, *n* (%)	95 (26.4%)
Alopecia totalis, *n* (%)	44 (12.2%)
Another type of alopecia areata, *n* (%)	30 (8.3%)

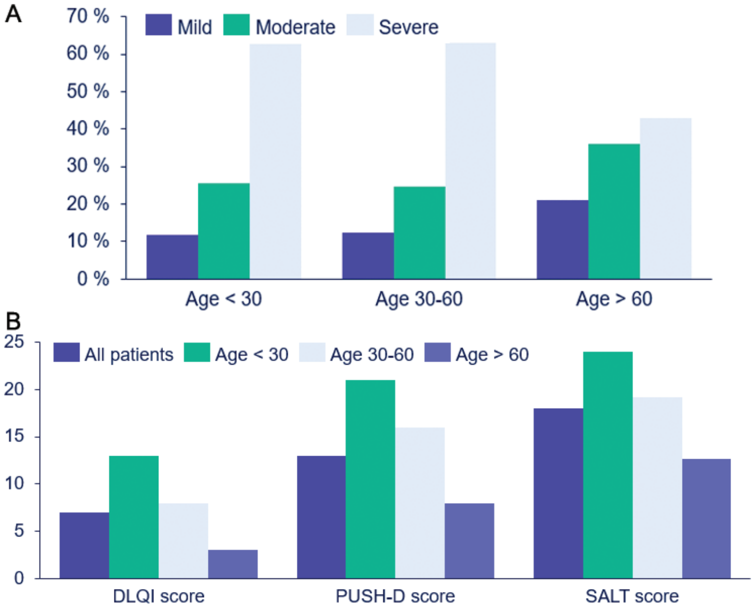

Fig. 1. Patients' self-perception of disease and self-assessment scores. (A) Self-reported disease perception per age group. (B) Self-reported Dermatology Life Quality Index (DLQI), Patient Unique Stigmatization Holistic tool in dermatology (PUSH-D), and Severity of Alopecia Tool (SALT) scores per age group.

Only 36% of the respondents had visited a healthcare professional within the last 12 months. Among those who did seek medical care, the median annual number of visits to dermatologists was 2, general practitioners 2, and psychologists 5 (**Table II**). The median age of respondents utilizing psychological services was 51 years. In total 14% of all respondents reported suffering from depression and 9% from anxiety. The median age of those reporting anxiety or depression ($n=59$) was 49 years (37.0–54.0), which is lower than the median age of the whole cohort.

The survey also revealed that 61% of participants reported that AA interfered with their daily or weekly activities. The daily/weekly interference was reported by 77% of respondents in the age group <30 years, 70% in age group 30–60 years, and 37% in age group 60+ years. Among those reporting daily or weekly disruption, 70% perceived their disease as severe.

SALT score and perception of severity

The relationship between SALT score and self-reported perception of disease severity (mild, moderate, or severe) was found to be weak, with an R-squared value of 0.369 ($p<0.001$). Among respondents with AA (excluding AT and AU), 25% reported their condition as mild, 38% as moderate, and 37% as severe. Interestingly, even within the group of patients who perceived their disease as severe, the distribution of SALT scores was relatively even (**Fig. 2**A). This suggests that patients' perception of severity is not solely tied to the extent of hair loss as measured by the SALT score.

Table II. Number of visits to healthcare professionals by responders during the last 12 months.

Resource use	Median (95% CI)*	*n*
Dermatologist	2.0 (2.0–3.0)	83
General practitioner	2.0 (1.0–2.0)	64
Nurse	4.5 (2.0–7.5)	6
Mental health worker (e.g., psychologist, therapist)	5.0 (3.0–10.0)	20

*95% confidence interval calculated with 1000 times repeated bootstrap method.

DLQI score and perception of severity

The correlation between DLQI scores and self-reported perception of disease severity (mild, moderate, or severe) was weak, with an R-squared value of 0.136 ($p=0.001$). The proportion of respondents with DLQI scores greater than 10 varied significantly across different perceptions of severity, with 0% of patients with mild disease reporting a DLQI score over 10, compared with 25% of those with moderate disease, and 47% in the severe group. In respondents with severe disease, the DLQI was evenly distributed, with 53% reporting DLQI score above 10 and 47% below 10 (see Fig. 2A). There was no statistically significant difference in DLQI scores between patients who reported an improvement or worsening of their condition over the past 12 months ($p=0.235$) (Fig. 2B). Among those who reported improvement ($n=132$), 58% had a DLQI score of 10 or lower, while 42% scored higher than 10. Among those who reported their condition had worsened ($n=54$), 67% had a DLQI score of 10 or lower, while only 33% had a score higher than 10. Among patients reporting daily/weekly impact of AA, 55 % had a DLQI above 10 and 45% below 10.

The association between DLQI and SALT scores was poor (R-squared$=0.08$, $p<0.001$), indicating that the degree of hair loss does not correlate strongly with QoL scores (**Fig. 3**).

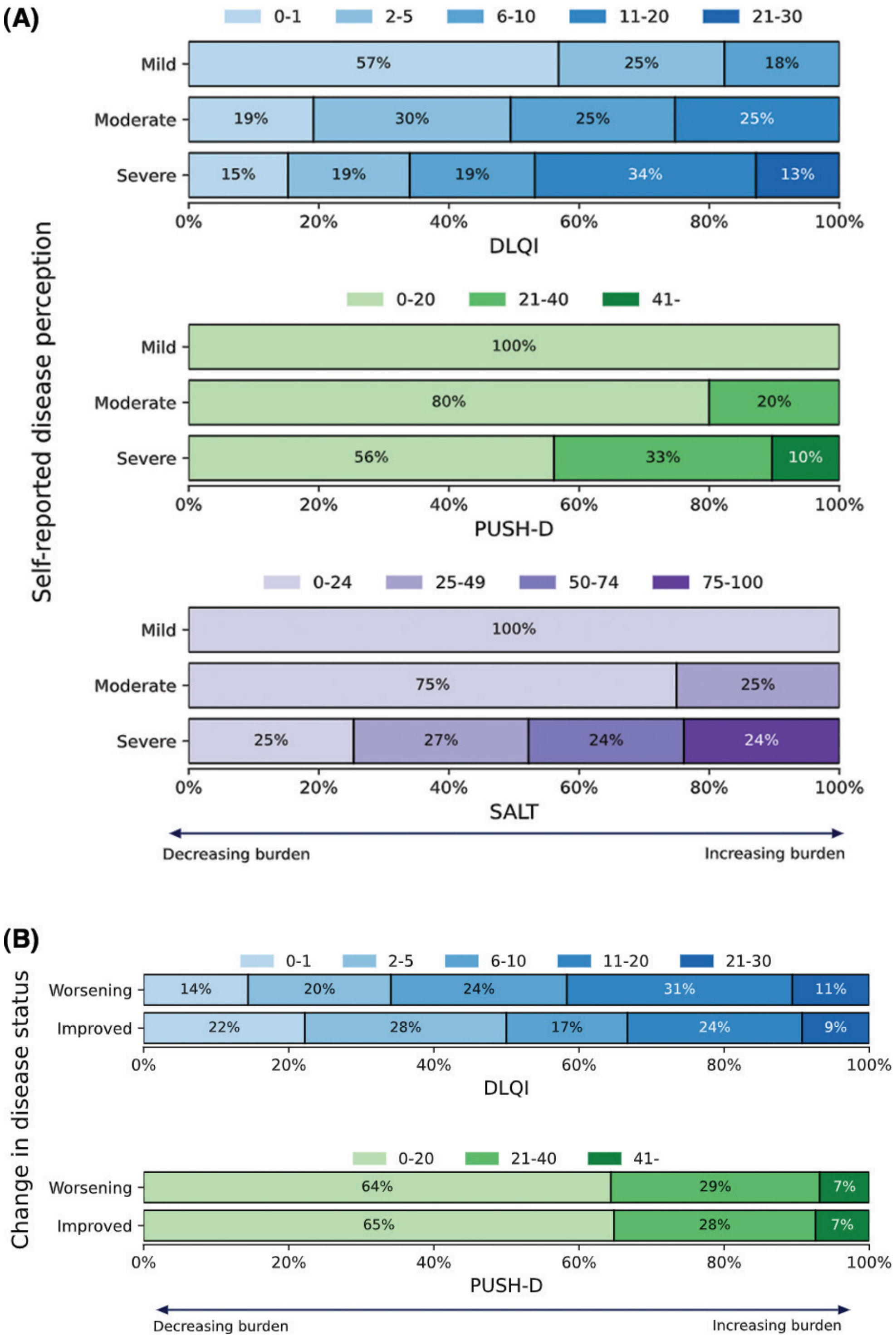

Fig. 2. Overview of assessment tools. (A) Overview of Dermatology Life Quality Index (DLQI), Patient Unique Stigmatization Holistic tool in dermatology (PUSH-D), and Severity of Alopecia Tool (SALT) by patient-reported severity perception. (B) Overview of DLQI and PUSH-D stratified by worsening or improved disease status over the past 12 months. All participants were asked to simply rate their disease as mild/moderate or severe. In addition, they answered the DLQI/PUSH-D questionnaires and self-reported on SALT score. The overview compares the patient's disease perception with the actual values based on disease scores. The X-axis include DLQI, PUSH-D and SALT score intervals commonly used to differentiate severity in clinical practice.

PUSH-D score and perception of severity

There was a moderate correlation between PUSH-D and DLQI scores ($R=0.67$, $p<0.001$). The proportion of patients with a PUSH-D score above 20 was 0% in those with mild disease perception, 20% in those with moderate disease, and 44% in those with severe disease (see Fig. 2A). However, similar to the DLQI, the PUSH-D score did not differentiate between patients who reported their condition had worsened or improved within the last year

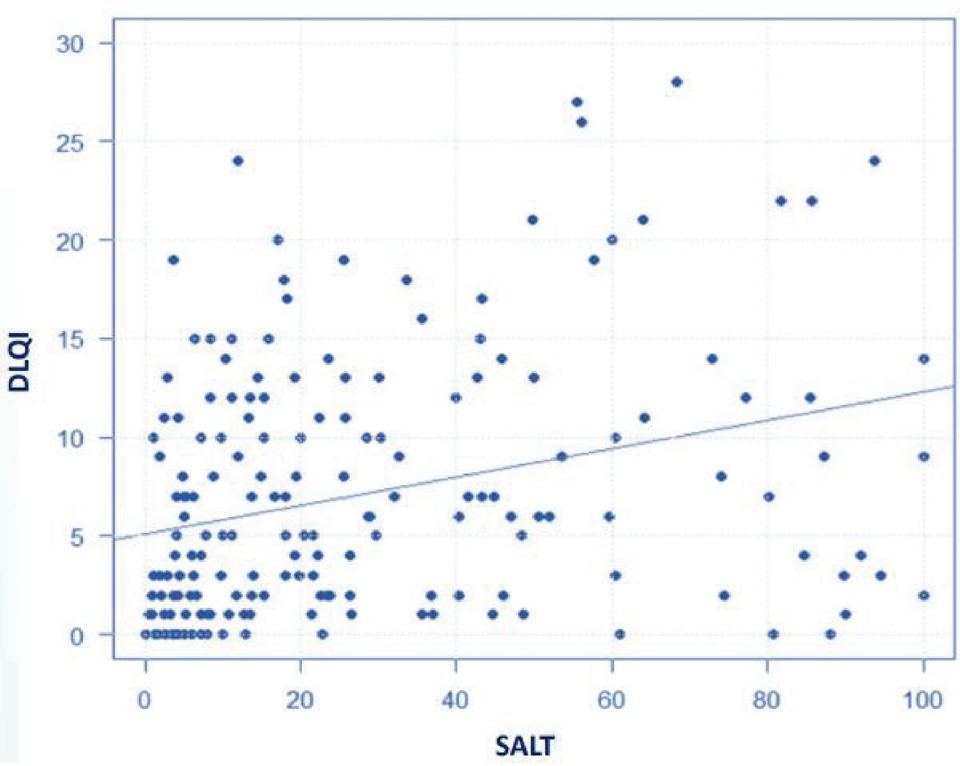

Fig. 3. Association between Dermatology Life Quality Index (DLQI) and Severity of Alopecia Tool (SALT) score.

($p=0.110$, see Fig. 2B) and did not mirror patients experiencing the impact of AA, as only 49% of those reporting daily/weekly impact had PUSH-D scores higher than 20.

DISCUSSION

The most important finding of this study was the disparity in AA between QoL measures and patients' own disease perception and impact. The DLQI score may not fully capture the impact of AA on patients' QoL. Although it provides insight into how skin conditions affect patients, it lacks specificity for hair loss disorders like AA. In particular, DLQI does not seem to differentiate between patients whose condition has improved and those whose condition has worsened. As a QoL measure, DLQI also failed to mirror patients who experienced daily/weekly impact due to AA. However, a DLQI score above 10 is currently required as a criterion by the Danish AA guidelines to initiate systemic treatment. Furthermore, if DLQI below 5 is not achieved within 36 weeks, the guidelines suggest stopping treatment (15). Short-term changes in disease severity may not lead to major changes in QoL. Guidelines and evolving research suggest further development and validation of AA-specific instruments for monitoring the impact of AA on QoL and assessment of treatment (16, 17, 18). Alopecia Areata Patient Priority Outcomes (AAPPO), which addresses hair loss, emotional symptoms, and activity limitations of AA, is suggested as a suitable instrument for discriminating between clinically relevant groups of patients with AA (17).

The PUSH-D, while it correlated with the DLQI, also failed to differentiate between worsening and improving disease states. These findings suggest that neither the DLQI nor the PUSH-D is an ideal tool for assessing the QoL or disease burden in AA patients. However, PUSH-D seems to capture the psychosocial aspects and stigma experienced by the younger population especially, and is thus an important finding for healthcare providers. The finding could also mean that patients somehow learn to cope with the disease in the long run or find alternative ways to conceal the hair loss.

There was also a disparity between the self-reported SALT score and patient-reported disease severity, revealing the limitations of current tools in assessing the true severity and burden of AA. The SALT score, while useful in quantifying the extent of hair loss, fails to account for the personal significance of hair loss in different cultural and social contexts (19). Hair, for many, is more than just a physical attribute – it holds symbolic meaning, representing beauty, health, and social status. Consequently, even minimal hair loss can trigger feelings of distress, fear, and shame, which the SALT score does not reflect.

Given the limitations of these measures, there is a clear need for more disease-specific tools that can better capture the lived experience of AA patients. In order to achieve better treatment outcomes, there is a specific need to identify in particular those who may be suffering emotionally, even when their physical symptoms appear to be mild.

The emotional toll of AA can be devastating for many patients, regardless of the visible extent of hair loss (19). In addition to hair, the loss of eyelashes and eyebrows is considered psychologically burdensome (16). The psychological distress caused by AA can stem from the unpredictability of the disease course, social stigma associated with hair loss, and personal identity being closely tied to one's physical appearance. The loss of hair, particularly on the scalp and face, can disrupt a person's sense of self, identity, and social role, leading to feelings of vulnerability, shame, and anxiety. Individuals with AA are at higher risk of developing depression, anxiety, and other mood disorders compared with the general population. This is demonstrated by the rate of depression and anxiety reported in this survey and the need for frequent psychological care for some patients.

Our findings indicate that there are patients with relatively low SALT scores (representing less visible hair loss) who perceive their condition as severe. This highlights the fact that the psychosocial burden does not always correlate directly with the extent of hair loss. Even patients with patchy AA may experience significant emotional distress due to the social implications of the disease. For these individuals, every patch of hair loss represents a visible reminder of their vulnerability, leading to anxiety over worsening symptoms and social rejection.

Our findings highlight this, particularly in the high levels of stigmatization reported by younger patients on the PUSH-D scale. Many participants expressed feelings of embarrassment and alienation, which significantly impacted their daily lives. This aligns with previous research showing that hair is not merely cosmetic but plays a critical role in individual identity and social interactions. The loss of hair, therefore, represents not just a physical change but a profound alteration in one's self-concept and public identity.

This study highlights the importance of adopting a more comprehensive approach to AA management. The psychosocial aspects of the disease must be taken as seriously as the physical manifestations. While therapies aimed at promoting hair regrowth remain a priority, clinicians should also address the emotional and psychological well-being of their patients. It is critical that healthcare providers recognize that even minimal hair loss can have a profound impact on a patient's mental health, especially in patient segments where hair plays a significant role in defining beauty and normalcy.

This study opens several avenues for future research in AA. One key area is the development and validation of disease-specific QoL tools that better capture the unique challenges faced by individuals with AA. These tools should not only assess physical symptoms but also consider the emotional and social dimensions of the disease.

Another important area for future research is the exploration of gender and age differences in disease perception and psychological impact. While this study was predominantly female, understanding how male patients experience and cope with AA is essential, especially as societal norms regarding hair loss can differ between men and women. Male patients may face different social pressures and may respond differently to their condition, both emotionally and psychologically. Studies that include a more balanced gender representation could offer new insights into these gender-based differences. A higher proportion of young respondents reporting worse in all disease and QoL measures clearly indicate that younger patients are more impacted by this disease. Additionally, there is a need to examine the long-term psychological outcomes of patients with AA, particularly young patients and those with severe disease perception. Longitudinal studies that track patients over time could help identify the factors that contribute to increased vulnerability to depression and anxiety.

Finally, given the rapid advances in AA treatments, such as Janus kinase (JAK) inhibitors and other targeted therapies, future research should investigate how these new treatments affect not only hair regrowth but also patients' QoL and mental health. It would be valuable to assess whether patients who experience regrowth with these therapies also experience improvements in self-esteem, social functioning, and emotional well-being.

Limitations

While this study offers important insights into the relationship between disease severity and patient perception in AA, several limitations must be acknowledged. The reliance on self-reported SALT scores is a potential source of error in this study. Self-assessments are inherently subjective and may not accurately reflect the true extent of the disease. In clinical settings, objective assessments by dermatologists are typically used to obtain more accurate measurements. The study population was predominantly female, with only 5% of respondents identifying as male. In general, females are more likely to answer surveys and this gender imbalance limits the generalizability of the findings. Given that hair loss is more socially acceptable for men, it is possible that male patients experience AA differently, both emotionally and psychologically. Participants in this study were recruited through social media platforms, which may introduce selection bias. Individuals who are more engaged with social media, and particularly those who participate in online AA communities, may have different experiences, perceptions, and knowledge of their disease compared with those who are less engaged, which could potentially skew the results.

Conclusion

This study suggests that DLQI, a commonly used score to measure impact on QoL in skin diseases, fails to mirror self-reported AA severity. It does not reflect the psychosocial and emotional dimensions of the disease as well as the physical challenges of daily life with AA. While objective measures, such as SALT score, provide valuable insights into the physical manifestations of AA, these do not capture the patient's experience and impact on daily life. The emotional and psychological burden of AA, particularly feelings of stigmatization, social isolation, depression, and anxiety, must be given greater consideration in both clinical practice and research, especially in young patients. Development of validated, AA-specific tools that can accurately reflect the physical, emotional, psychological, and social challenges are essential for appropriate management and addressing individual needs of patients with AA.

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Conflict of interest disclosures: AGF and RM are employees of Pfizer and own stocks in the company. STG is a former employee of Pfizer. PV and A-KA are employees of Nordic Healthcare Group, responsible for study conduct, contracted by Pfizer. The remaining authors declare no conflicts of interest.

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