


Perceived Stress, Illness and Stigma in Patients with Alopecia Areata

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Alopecia areata is a nonscarring autoimmune hair loss disorder. Little is known about patients' perceptions of their condition. This French cross-sectional online study primarily aimed to assess patients' perception of stress as a causal factor, with secondary objectives examining illness perception and stigma. Adults aged ≥ 18 years with a confirmed alopecia areata diagnosis were included. The primary outcome was patients' attribution of stress as a cause of alopecia areata, while secondary outcomes included IPQ-R and PUSH-D scores. Among 96 participants, there was a strong female predominance (15.6:1) and a high proportion of alopecia totalis (65%). Stress was identified as a cause by 52 patients (54%), and this belief was shared by their dermatologist in 18 cases (35%). Patients reported significant emotional consequences, major life impact and a chronic course. Those attributing alopecia areata to stress showed higher perceived personal control (15.3 \pm 4.9 vs. 12.7 \pm 4.3; $p=0.006$). The mean PUSH-D score was 18. Poorer perceived consequences and stronger emotional representations correlated with greater stigma ($p=0.56$; $p=0.59$; $p<0.05$), while lower disease understanding correlated with higher stigma ($p=-0.34$; $p<0.05$). Integrating educational programmes into routine care may enhance patients with alopecia areata understanding and coping.

Key words: adaptation; psychological; alopecia areata; stigma.

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Alopecia areata (AA) is an autoimmune disorder characterized by transient, nonscarring hair loss and hair follicle preservation. Hair loss can take many forms ranging from well-defined patches to diffuse or even total hair loss, which can affect all hair-bearing sites. AA has a lifetime incidence of 2% and no gender predominance (1). The high level of psychosocial

SIGNIFICANCE

Alopecia areata is a non-scarring autoimmune hair loss disorder with a documented impact on quality of life. This French study conducted online investigated how patients perceive stress, their illness and stigma, using the *Illness Perception Questionnaire-Revised* (IPQ-R) and the *Patient Unique Stigmatization Holistic tool in Dermatology* (PUSH-D). Among the 96 participants, 52 (54%) considered stress to be a potential cause. Patients reported major life impact, strong emotional consequences and a belief in a chronic course, alongside low understanding and limited perceived control. Stigma was relatively high, with a PUSH-D score of 18. Educational programmes may strengthen patient understanding and management.

burden from AA is evident, and it is consistently documented in scientific literature (2). The pathogenesis of AA involves genetic and immune factors (3). Several genetic susceptibility loci were identified as being associated with signalling pathways that are important to hair follicle cycling and development. Pathophysiology of AA involves immune privilege collapse in the hair follicle (4), which is thought to render the hair follicle susceptible to attack by natural killer and autoreactive CD8+T cells. Cytokines implicated in pathogenesis, including interferon- γ and interleukin-15, depend on Janus kinases (JAKs) for intracellular signalling. Consequently, Janus kinase inhibitors (JAKi) have ushered in a new era in AA. Although we now know that AA is not caused by stress, there are many publications linking emotional stress to alopecia relapse (5). Indeed, a variety of trigger factors have been proposed but the most commonly reported are emotional and/or physical stress, such as following a bereavement or injury (6, 7). The controversial role of psychosocial stress in alopecia areata has been widely discussed but there has been little research into patients' subjective stress experiences and coping (8). Furthermore, illness perception has been shown to play a predictive role in health outcomes in many illnesses (9).

In a recent article, Christou et al. found that alopecia areata has a severe psychosocial impact, which is more

closely related to the patients' illness perception and stigma than AA severity (10).

The main objective of our observational study using social media was to evaluate patients' perceptions of the contribution of stress in the development of their AA. The secondary objective was to investigate the illness perception and stigma of patients with AA.

MATERIALS AND METHODS

This cross-sectional observational study took place from March 2024 to June 2024. A short description of the study detailing the aims and purpose of the study was first advertised on the Facebook group «*Pour parler de la pelade (alopécie)*» (group of patients having specifically AA) and the Instagram page «*La Tresse*» (group of patients having diverse causes of alopecia). All members of the social network communities who expressed the will to participate had access to the questionnaires after clicking on a dedicated link to access the questionnaires. We designed the questionnaires with the aim of guaranteeing participants' anonymity.

Inclusion criteria were adults 18 years and older; being a member of either «*Pour parler de la pelade*» or «*La Tresse*»; and confirmed alopecia areata by the «Auto-Diagnostic questionnaire for Alopecia areata» (11).

Patients were redirected to Sphinx Declic software to fill out 3 self-reported questionnaires. All participants had to answer every item of the questionnaires to be able to complete the study in order to prevent missing data.

The first questionnaire «Personalized patient questionnaire» included a validated self-diagnostic questionnaire for AA (12), patients' general data (gender, age, education, personal and family history of AA) and the item: "Do you think stress could be a cause of your alopecia areata?" (Appendix S1).

The second questionnaire was the validated French version of the «Illness Perception Questionnaire-Revised (IPQ-R)» (13) which studies illness perception in terms of one's personal beliefs surrounding AA. (Appendix S2) It contains 9 sub-scales: 1: identity, which refers to the occurrence of general symptoms and their relation to the disease, 2: consequences of the illness, 3: illness coherence which means understanding of the illness, 4: belief in personal control, 5: belief in treatment control, 6: timeline acute/chronic which stands for the expected duration of illness, 7: timeline cyclical, which stands for the variability of symptoms over time, 8: emotional representations associated with the disease and 9: the disease's suspected cause. The identity scale is answered yes or no. All further items are assessed on a 5-point Likert scale from "strongly disagree" to "strongly agree." All items for each of the subscales are summed to

give an overall score. High scores on the identity, consequences, timeline acute/chronic and cyclical sub-scales represent strongly held beliefs about the number of symptoms attributed, the negative consequences, the chronicity and the cyclical nature of the illness. High scores on the personal and treatment control and coherence sub-scales represent positive beliefs about self-control, treatment efficacy and a personal understanding of the illness (14).

The third questionnaire was the validated «Patient Unique Stigmatization Holistic tool in Dermatology (PUSH-D)» (15) consisting of 17 items measuring two dimensions of stigma: felt stigma (8 items) which refers to an individual's feelings of embarrassment in addition to the anticipation and expectation of discrimination and enacted stigma (9 items) which refers to the perception of discrimination by individuals with a stigmatising disease. The PUSH-D uses a 5-point Likert scale: "never" or "not applicable" (rated 0), "rarely" (1), "sometimes" (2), "often" (3), "very often" (4). Each item is introduced by the sentence "During the last month" to define a precise time frame and limit recall bias. The PUSH-D global score is the sum of all items, ranging from 0 (no stigma) to 68 (representing a high level of experienced stigma).

Participation in this study was voluntary, and no incentives were offered. This study was approved by the Ethics Committee of Brest University Hospital on 14 March 2024. No written informed consent had to be obtained from the participating patients and they were provided with an information and non-objection note.

Statistical analysis

Basic summary statistics, such as proportions, means and standard deviations, were used to characterize population attributes.

In a second step, descriptive characteristics were assessed according to the presence vs absence of stress (stress+group vs stress- group), based on the ninth question of the personalized patient questionnaire "Do you think stress could be a cause of your alopecia areata?", and using a two-sided Student *t*-test via BiostaTGV software. Statistical significance was defined as $p < 0.05$.

Spearman correlation coefficients were used to investigate the relationship between illness perceptions and the PUSH-D score.

RESULTS

A total of 101 patients completed the questionnaires. 96 participants (90 females) were included, as illustrated in Fig. 1.

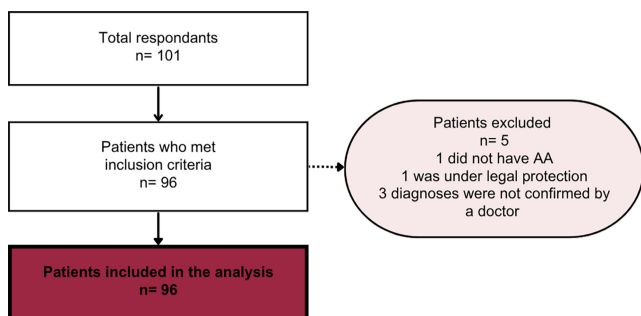


Fig. 1. Flowchart of the study.

Personalized patient questionnaire

Ninety-three individuals acknowledged that their AA was confirmed by a dermatologist. Most patients were aged between 25 and 34 years (31%). Fig. 2 shows the age distribution. Patients with a high level of education represented 72% of responders and 65% of responders declared AA totalis (AT) while 36% had patchy AA. In addition, 69% declared eyebrow involvement while 54% had eyelash involvement. Among participants, 59% used either a wig, headscarf or turban in their daily life. 49% had a long-lasting form (more than 10 years) of alopecia areata. First-degree family history of alopecia areata was found in 19% of responders (Table I).

54% of patients responded “yes” when asked if they thought stress could be a cause of their AA. This idea was shared by their relatives for 37 (71%) of them and by their dermatologist for 18 (35%) of them.

Among these 54% patients, 6 (12%) believed that stress was even the only cause. Twenty-one patients underwent psychological follow-up, including 10 patients with the objective of learning to manage their condition, 11 patients seeking to manage their condition while pursuing healing, and one patient whose sole objective was healing.

Assessment of illness perception

Identity subscale. The most common symptoms perceived by the patients as related to their disease were

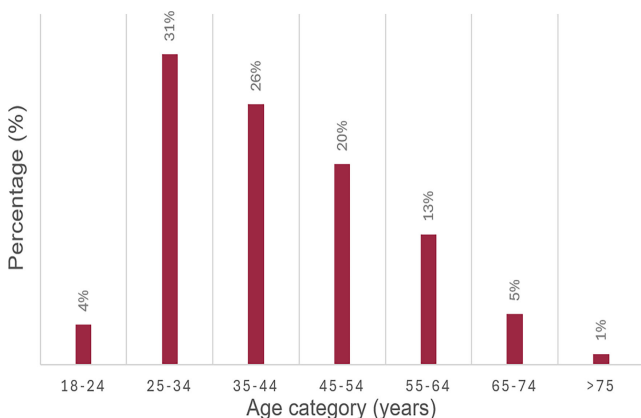


Fig. 2. Age distribution of the participants.

Table I. Sociodemographic data and disease characteristics of the participants (AA patients = 96)

	N	%
Gender		
Female	90	94%
Male	6	6%
Median age (IQR)	39.5 (20)	
Mean age	42	
Level of education		
No diploma	1	1%
Baccalaureate/ National Vocational	25	26%
Qualification		
Higher education	69	72%
Other (no specification)	1	1%
AA type *		
Patchy AA	35	36%
AA totalis (AT)	62	65%
Use of a wig/headscarf/turban		
Yes	57	59%
No	39	41%
Duration of disease		
<1 year	10	10%
1-5 years	27	28%
5-10 years	12	13%
>10 years	47	49%
1 st degree family history of AA		
Yes	18	19%
No	78	81%

* 1 patient both answered “patchy AA” and “AT”.

fatigue (29%), sleep difficulties (26%), sore eyes (21%) and pain (16%).

Causal subscale. The most frequently cited causes by patients were altered immunity (mean=3.77), chance (mean=3.43) and stress (mean=3.33). When asked to identify the primary cause of their illness, stress was reported by 43% of patients, autoimmunity by 28%, heredity by 6% and chance by 6%.

Beliefs about long-lasting and the cyclical timeline. 79% of patients perceived AA as a chronic illness (mean score=24.8 ± 4.7).

51% of patients believed their condition was rather cyclical (mean score=11.8 ± 4.0) with a range of 4 to 20. (Table II) We found that patients from the “stress group” had a stronger belief of a cyclical timeline (mean score=13.2 ± 3.5) compared with patients from the “no stress group” (mean score=10.1 ± 4) $p=0.0002$ (Table III).

Beliefs about consequences and emotional representations. 82% of patients believed the consequences of alopecia areata were important in their lives (mean score=20.7 ± 4.2), and this was not significantly different between the 2 subgroups (mean score in the “stress group”=20.9 vs mean score in the “no stress group”=20.6; $p=0.73$) (Table III).

We also noted significant negative effects of illness on the patient’s emotions (mean score=21.4 ± 6.2), and these results did not differ significantly between the two subgroups (mean score in the “stress group”=22.5 vs mean score in the “no stress group”=20.2; $p=0.07$) (Table III).

Table II. Scores of revised illness perception questionnaire in patients with alopecia areata (AA)

Questionnaire dimension	Score range	Median reference score of questionnaire	Median score of AA patients	Mean score \pm SD of AA patients	Min-Max score of AA patients
Timeline : Acute/chronic	6-30	18	25	24.8 \pm 4.7	14-30
Consequences	6-30	18	21	20.7 \pm 4.2	10-29
Personal control	6-30	18	14	14.1 \pm 4.8	6-28
Treatment control	5-25	15	12	11.9 \pm 4.6	5-21
Illness coherence	5-25	15	13	13.1 \pm 4.6	5-25
Timeline : Cyclical	4-20	12	12	11.8 \pm 4.0	4-20
Emotional representations	6-30	18	22	21.4 \pm 6.2	6-30

84% of patients reported being disturbed by their illness. Almost 60% experienced anxiety due to their condition. (Table II)

Beliefs about personal and treatment control. 60% of patients thought that their actions could influence their condition (mean score=14.1 \pm 4.8). Almost half of the patients (49%) believed that the illness could not be controlled therapeutically (mean score=11.9 \pm 4.6) (Table II).

Our subgroup analyses showed that patients from the "stress group" had a higher personal control (mean score=15.3 \pm 4.9) than the "no stress group" (mean score=12.7 \pm 4.3) $p=0.006$, and a higher treatment control (mean score=12.9 \pm 4.4) than the "no stress group" (mean score=10.8 \pm 4.6) $p=0.027$ (Table III).

Beliefs about illness coherence. 24% of patients had a clear understanding of their condition (mean score=13.1 \pm 4.6) (Table II).

Patient Unique Stigmatization Holistic tool in Dermatology (PUSH-D).

The mean PUSH-D score was 18 (range 0-59).

We performed a subgroup analysis to evaluate whether AA duration had an impact on experienced stigmatization: there was no difference in the mean PUSH-D score between recent forms (1 year) (mean score=18.2) and chronic forms (>10 years) of AA (mean score=17.6) (Fig. 3).

We also performed a subgroup analysis to assess whether patients who believed that stress was a cause of their AA had a similar mean PUSH-D

score: there was no significant difference: 18.44 (range 0-59) for the group "stress" vs 17.39 (range 2-46) for the "no stress group" ($p=0.64$).

We used Spearman correlation test to examine the link between the IPQ-R subscales and the PUSH-D score: important consequences and negative emotional representations showed a strong and statistically significant correlation with stigma (respectively $\rho=0.56$; $p=3.3096787648661116e-09$ and $\rho=0.59$; $p=2.516360846988953e-10$), alongside a poor understanding of the illness ($\rho=-0.34$; $p=0.00062028457966554$).

DISCUSSION

This cross-sectional observational study based on social media is the first French study to investigate patients' perception of stress as a cause of AA.

Most participants in the study were young adults, with a female predominance (female-to-male ratio of 15.6:1) and widespread involvement of hair loss (65% had alopecia totalis).

In the personalized questionnaire, 52 patients (54%) indicated that stress may be a causal factor in AA. In the IPQ-R causal subscale, patients were asked to identify the primary cause of their illness: 43% patients reported stress, while 28% patients reported autoimmunity. These results show that even in this well-informed population, aware of both the condition's complexity and its autoimmune component, stress is often cited as a causative factor. Similarly, Nasimi et al. found that AA patients assumed the most common cause of their condition was stress. Firooz et al. reported that stress played a role in the onset of AA in 76.9% of patients (16).

Furthermore, the notion of stress as a causal factor of AA was shared by patients' relatives in 71% of cases and by their dermatologists in 35% of cases.

The pathophysiology of alopecia areata has been the subject of increased research in recent years, leading to a more comprehensive understanding of the condition. It is now recognized as an autoimmune disease (17), with mounting evidence attributing a central role to the immune system in its pathophysiology. There is also compelling evidence that stress and autoimmunity are linked (18). Indeed,

Table III. PQ-R subgroup analyses "stress group" vs "no stress group"

Questionnaire dimension	Score range	Mean score \pm SD of "stress" group	Min-Max score of "stress" group	Mean score \pm SD of "not stress" group	Min-Max score of "not stress" group	p-value [IC 95%] T-student
Timeline: Acute/chronic	6-30	24 \pm 4.8	14-30	25.7 \pm 4.4	17-30	
Consequences	6-30	20.9 \pm 3.9	12-29	20.6 \pm 4.4	10-29	0.73 [-1.4186 ; 2.013]
Personal control	6-30	15.3 \pm 4.9	6-28	12.7 \pm 4.3	6-24	0.006 [0.7491 ; 4.4887]
Treatment control	5-25	12.9 \pm 4.4	5-21	10.8 \pm 4.6	5-21	0.027 [0.2358 ; 3.9041]
Illness coherence	5-25	13.1 \pm 4.9	5-25	13.1 \pm 4.2	5-22	
Timeline: Cyclical	4-20	13.2 \pm 3.5	4-20	10.1 \pm 4	4-19	0.0002 [1.493 ; 4.5804]
Emotional representations	6-30	22.5 \pm 5.8	9-30	20.2 \pm 6.6	6-30	0.07 [-0.2168 ; 4.8601]

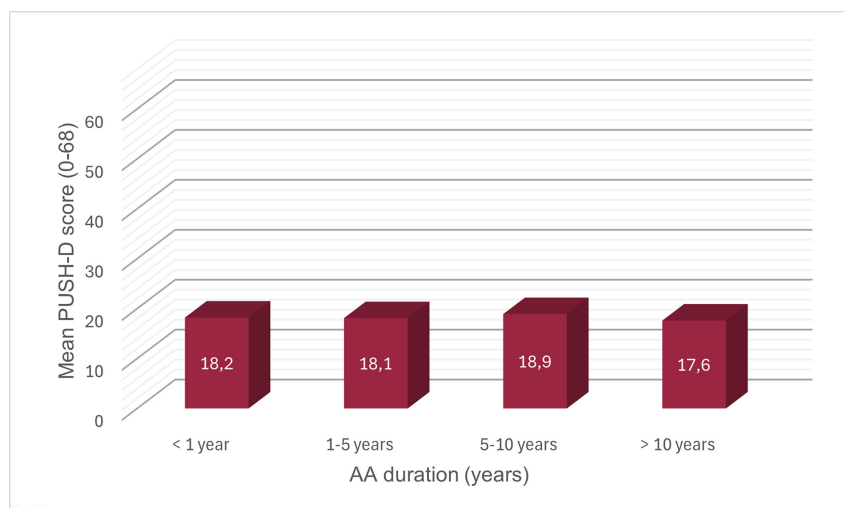


Fig. 3. Subgroup analyses: mean PUSH-D score depending on AA duration.

many of the major pro-inflammatory cytokines such as IL-6, IL-1b and TNF- α are upregulated in response to physiological and/or psychological stress (19). While stress may be implicated as a modulating factor, as has been suggested in the context of all autoimmune diseases, the concept of alopecia areata being solely attributable to stress is currently considered as irrelevant. However, patients rarely make differences between an etiological factor and a trigger for flare-ups.

Dermatologists play a pivotal role in patients' education, comprehension of their illness, and the deconstruction of popular misconceptions.

Also, the causal attribution of the condition deserves attention, as the findings of Willemse et al. (20) suggest that attribution to internal causes is associated with more maladaptive avoidance coping, whereas attribution to chance may exert a direct positive influence quality of life. An explanation could be that ascribing a condition to chance or bad luck which not only eliminates possible feelings of regret, frustration or sorrow regarding past actions believed to have caused the condition and might limit patients believing they have to make lifestyle adjustments.

Hair has social and psychological significance beyond its biologic function. The high level of psychosocial burden from AA is evident and well documented (21).

On the illness dimension sub-scale of the IPQ-R, patients perceived their disease as having important consequences on their lives and a strong emotional impact.

Our findings showed that patients with AA correctly experienced their condition as a chronic illness. Those results are in accordance with the selected population who presented a predominantly chronic form of the illness. Despite the assumption that belonging to a support group increases patients' understanding of their condition, the level of illness coherence was

moderate (24%). Additionally, less understanding of AA was associated with higher stigma level. Educational programmes in addition to standard care in AA should focus on understanding pathophysiology of the disease and regulating negative emotionality. Interestingly, our French e-cohort had lower mean scores for personal control (14.1 vs 20.3) and treatment control (11.9 vs 18.1) in comparison to 102 AA patients recruited in an alopecia clinic (22). These observed differences might result from the fact that the patients using social media were mainly suffering from severe and chronic forms of AA. Personal control and treatment control were significantly higher in the "stress group" than in the "no stress group". In the literature, higher scores on the dimensions personal and treatment control indicate more positive illness perceptions (23). However, this finding may also suggest that patients who attribute their AA to stress feel more involved in their condition, thus raising the question of the guilt this belief may generate. Strong beliefs of self-blame in developing a condition are associated with psychological distress in other dermatological diseases. Indeed, Fortune et al. reported that patients believing in emotional causes were more likely to feel in some way responsible for the onset or exacerbation of their psoriasis (24). The cyclical timeline demonstrated a marked increase in the stress attribution group, indicating that alopecia areata appeared to be more erratic in this group. Overall, the emotional reactions to AA and the expected effects were not higher in the "stress group".

PUSH-D is a recently validated tool in dermatology, that has not previously been used in a study on alopecia areata (25). It has been assessed in vitiligo in a French e-cohort of 318 patients, with a mean PUSH-D score of 11.03 (range 0–55) (26). In addition, an anchor question was added in the vitiligo study to identify severity strata for the PUSH-D. We found a relatively high PUSH-D stigma score of 18 (range 0–59) but unfortunately, we did

not include an anchor question in our study. A French e-cohort of 1,250 adults with Atopic Dermatitis (AD) also found a lower PUSH-D score of 14.22. (27) This may indicate that French AA patients feel more stigmatized than vitiligo and AD patients. However, comparisons have to be cautious and can vary according to the populations and the questionnaires (28). PUSH-D scores were found to be comparable between patients with recent and chronic forms of AA showing that stigmatisation doesn't disappear with time. Indeed, 49% of participants had a chronic form of AA (lasting more than 10 years) and yet were still active members of an online support group, highlighting the difficulty of coping with AA despite living with it for a long time. The emergence of new treatments such as JAK inhibitors may influence patients' perception of their condition.

Online recruitment has several advantages: it is a cost- and time-effective technique in observational studies (3) and makes it possible to target so-called "hard-to-reach" populations (socially disadvantaged, (e.g. because of their social background, ethnicity, low income, difficult access to the health system) (6).

Our study had limitations including a small sample size and a selection bias due to an exclusive social media recruitment strategy. The sample population was indeed dominated by young females (25–44 years old) highly educated and consequently lacked representativity. Nonetheless, this demographic profile aligns with that observed in other online recruitment studies (12, 18).

This is the first French study that investigated AA patients' perception of stress in their condition.

More than half of patients thought stress may be a cause of their disease and approximately one-third of the dermatologists treating these patients expressed a similar opinion according to participants. This belief prompts the question of whether it could engender guilt in some patients. Less understanding of AA was associated with higher stigma level. Educational programmes in addition to standard care in AA should focus on understanding pathophysiology of the disease and regulating negative emotionality.

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Data Availability: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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The authors have no conflicts of interest to declare.

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