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Delays in Diagnosis of Alopecia Areata

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Keywords
Alopecia areata · Diagnostic delays · Healthcare disparities

Abstract

Introduction: Diagnostic delays in alopecia areata (AA) are often preventable and may be compounded by factors that have not been fully elucidated. Our objective was to identify potential associations and to characterize diagnostic delay of AA that extends beyond 1 year. ***Methods:*** Patients with AA were recruited via online survey. A multivariable linear regression was performed to analyze diagnostic delay greater than 1 year while controlling for age, sex at birth, race, income, health insurance, and employment. A sensitivity analysis was performed to compare delays of over 9 months versus 1 year. ***Results:*** Regression analysis revealed associations between white race (OR 0.46, 95% CI [0.27–0.80], $p = 0.006$), annual income above the median of $75,000 (OR 0.56, 95% CI [0.32–0.99], $p = 0.046$), and having health insurance (OR 0.32, 95% CI [0.11–0.92], $p = 0.034$), with lower odds of diagnostic delay beyond 1 year. Sensitivity analysis indicated that these associations, except health insurance, held true even at 9-month thresholds. ***Conclusion:*** Limitations include survey demographics and cross-sectional design, limiting causal inference. Socioeconomic factors, including race, income, and insurance coverage, extend diagnostic delay in AA. Addressing disparities could improve timely diagnosis for AA, emphasizing the need for further investigation of healthcare barriers.

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Plain Language Summary

Alopecia areata (AA) is a condition that causes hair loss when the immune system attacks hair follicles by mistake. Some patients with AA may experience a longer time before being diagnosed than others. Getting diagnosed early is important for patients with AA because it can help prevent further hair loss and mental health conditions. This study looked at survey data from 500 patients with AA to know how long it took them to be diagnosed and what factors played a role in any delays they experienced. The study found that some patients waited longer than 1 year before being diagnosed with AA. Those who were white, had higher incomes, or had health insurance were diagnosed earlier, meaning that those who were not white, had lower incomes, or did not have health insurance were more likely to experience longer delays. On average, patients waited

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about 9.6 months to be diagnosed, but some waited for over 20 years. The results suggest that race, financial status, and healthcare access make it more difficult for some patients to be diagnosed earlier. These delays can have serious effects, including mental health concerns, social difficulties, and high costs. This study had limitations, such as the fact that most survey participants were white women with an above average income, meaning the results may not be accurate for all patients with AA. More research is needed to fully understand the reasons behind delays and to find ways to improve diagnosis time in AA. © 2026 S. Karger AG, Basel

Introduction

Alopecia areata (AA) is an immune-mediated condition of hair loss [1, 2]. Patients with AA often experience preventable delays in diagnosis, which can exacerbate the emotional and psychological toll of the condition [3]. Early diagnosis is crucial, allowing for prompt treatment that can mitigate psychiatric comorbidity exacerbation, hair loss progression, and mental health deterioration [3–5]. Socioeconomic disparities, including lack of health insurance and financial constraints, often compound delays, leaving vulnerable groups at risk of worsened outcomes [6]. In this analysis of survey data from the National Alopecia Areata Foundation (NAAF), we aim to characterize delays in diagnosis of AA and to identify potential risk factors for delayed diagnosis.

Methods

This study utilized a cross-sectional internet survey by NAAF with a goal sample of 500 respondents. Participants were required to be over 18 years in age, to self-identify as having AA, and to have seen a provider for AA within the past year (online suppl. Fig. 1; for all online suppl. material, see https://doi.org/10.1159/000552679).

The primary outcome, delay in diagnosis, was defined as the time between first seeking medical attention for AA symptoms and receiving a diagnosis from a health professional. Patient-reported time to diagnosis was converted into years and dichotomized into greater and less than 1 year, with delays defined as diagnosis taking more than 1 year. A 1-year delay threshold was chosen to help standardize the definition of delay, as approximately 50% of patients experience spontaneous regrowth without intervention during this time [7].

A multivariable logistic regression was performed to assess the association between various socioeconomic factors and likelihood of delay in diagnosis. Variables included are age (continuous), sex at birth (male or female), race (white or non-white), income (above or below USD 75,000 per year), health insurance coverage, and employment status. A sensitivity analysis was performed to investigate how different delay thresholds, 1 year versus 9 months, affect the latter associations.

Results

A total of 500 individuals responded to the survey (online suppl. Fig. 1). During the initial survey screening, 351 respondents exited the survey before eligibility was determined. Five hundred five total respondents were confirmed eligible, but 5 declined to participate. Five hundred total respondents completed the survey, resulting in an overall response rate of 99%. Respondents were primarily married (54%), white and non-Hispanic (72.6%) women (86%) with an annual income of above USD 100,000 (34%) (Table 1). The average time to diagnosis was 0.80 ± 2.34 years, ranging from 0 to 20.42 years, with a median time to diagnosis of 0.083 years (approximately 1 month).

Multivariable logistic regression showed that respondents of white race (OR 0.46, 95% CI [0.27–0.80], $p = 0.006$), income above the median (OR 0.56, 95% CI [0.32–0.99], $p = 0.046$), and with health insurance (OR 0.32, 95% CI [0.11–0.92], $p = 0.034$) have significantly lower odds of experiencing diagnostic delay. Age, sex, and employment status were not predictive (Table 2).

Sensitivity analysis defining delay as time to diagnosis of 1 year versus 9 months showed that white race and income above the median were consistently associated with lower odds of delay. The directionality of the relationship with health insurance coverage remained, although it was not statistically significant at 9 months (online suppl. Table 1).

Discussion

This evaluation revealed an average delay to diagnosis time for patients with AA of 9.6 months. Sixty-six participants (13.2%) reported a delay of over 1 year in obtaining an AA diagnosis. For these patients, impact of time to diagnosis in treatment outcomes remains great, especially when evaluating disease cost on mental health,

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Table 1. Respondent demographics

Age, years	All respondents (*N* = 500)	Delay (*N* = 66)	No delay (*N* = 434)
Mean (SD)	50 (14.6)	51 (13.8)	50 (14.7)
Median	51	51	52
Annual income, *n* (%)			
Below USD 25,000	44 (8.8)	8	36
Below USD 75,000 but at least USD 25,000	153 (30.6)	25	128
Below USD 100,000 but at least USD 75,000	67 (13.4)	10 (15.2)	57 (13.1)
At least USD 100,000 or above	171 (34.2)	13 (19.7)	158
Declined to answer	65 (13.0)	10 (15.2)	55
Biological sex at birth, *n* (%)			
Male	68 (13.6)	10 (15.2)	58 (13.4)
Female	431 (86.2)	56 (84.9)	375 (86.4)
Other	1 (0.2)	0	1 (0.2)
Education, *n* (%)			
Less than high school	7 (1.4)	4 (6.1)	3 (0.7)
High school graduate or GED	485 (97)	62 (93.9)	423 (97.4)
Declined to answer	8 (1.6)	0	8 (1.9)
Health insurance status, *n* (%)			
Has health insurance	480 (96.0)	60 (90.9)	420 (96.8)
Does not have health insurance	18 (3.6)	6 (9.1)	12 (2.8)
Declined to answer	2 (0.4)	0	2 (0.4)
Marital status, *n* (%)			
Single, never married	117 (23.4)	12 (18.2)	105 (24.2)
Living with partner	24 (4.8)	5 (7.6)	19 (4.4)
Married	271 (54.2)	37 (56.1)	234 (54.0)
Separated	3 (0.6%)	0	3 (0.7%)
Divorced	67 (13.4%)	10 (15.2%)	57 (13.1%)
Widowed	13 (2.6%)	2 (3.0%)	11 (2.5%)
Declined to answer	5 (1.0%)	0	5 (1.2%)
Racial and ethnic identity, *n* (%)			
White, not Hispanic	363 (72.6)	38 (57.6)	325 (74.9)
Hispanic	52 (10.4)	13 (19.7)	39 (9.0)
African American	44 (8.8)	10 (15.2)	34 (7.8)
Asian	25 (5.0)	1 (1.5)	24 (5.5)
Other	16 (3.2)	4 (6.1)	12 (2.8)

Table 2. Effects of socioeconomic factors in AA diagnosis exceeding 1 year

	Odds ratio (95% CI)	*p* value
Age at time of survey	1.02 (0.99, 1.04)	0.163
Sex at birth	1.07 (0.51, 2.27)	0.860
White race	0.46 (0.27, 0.80)	0.006
Above median (USD 75,000) income	0.56 (0.32, 0.99)	0.046
Health insurance coverage	0.32 (0.11, 0.92)	0.034
Employment status	0.65 (0.14, 2.01)	0.185

Overall regression significance: $p = 0.005$. Multivariable logistic regression of delays exceeding 1 year to diagnosis of AA and socioeconomic factors. Age at time of survey was a continuous variable. All other variables in the logistical regression were binary.

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time needed for hair regrowth, and expenditures on hair loss concealment methods.

Extended delays of greather than 1 year were significantly more likely in patients who were non-white, who were lower income, and who lacked health insurance. Sensitivity analysis demonstrated that the associations between socioeconomic factors and delays in AA diagnosis are consistent at both 1-year and 9-month thresholds. These results highlight the variability in time to diagnosis for patients with AA and resonate with existing literature that highlight systemic barriers faced by non-white and lower income populations in accessing timely healthcare services across diseases [6].

Delays remain a significant and preventable cause of worsened outcomes and exacerbated psychiatric comorbidities; a phenomenon not solely ascribed to AA. For example, a recent 2023 study in hidradenitis suppurativa showed that a delay in diagnosis of over 5 years was significantly associated with psychiatric and cardiovascular comorbidities [8]. The history of significant delays in diagnosis of hidradenitis suppurativa demonstrates both the importance of timely diagnosis as well as the persistence of systemic barriers that are not new to medicine, but that continue to impact dermatologic outcomes.

Limitations in our study include the cross-sectional design, limiting the ability to infer causality, as well as survey demographics, which reflected NAAF survey participants, and may not fully represent the broader population of patients with AA. For instance, our study population was primarily female and had a mean age of 50. This contrasts with the most recent epidemiological data available on AA, in which the highest incidence rates were found to be in adult females between the ages of 30 and 34 [9]. Additionally, the underrepresentation of non-white participants in our sample may result in an underestimation of the true prevalence of diagnostic delay of AA and an inability to evaluate impact across racial and ethnic subpopulations. The discrepancy in our sample's representativeness relative to the context of overall AA epidemiology emphasizes the importance of future research to include a more diverse sample, longitudinal studies, and additional variables such as geographic location and healthcare access to better characterize the underlying causes of delay. Ultimately, whether the skewed distribution and presence of outliers in diagnosis times suggest healthcare misuse, misdiagnosis, or referral delays as causes for extended delays remains to be elucidated; however, the importance of recognizing and addressing diagnostic delays in AA to improve clinical outcomes is irrefutable.

Statement of Ethics

This study protocol was reviewed and approved by Pearl IRB, approval #21-CERN-106. It was determined to be IRB-exempt through this approval and received subsequent approval from NAAF to be conducted. The Ethical Review Committee of the Mass General Brigham Institutional Review Board (REDCap ID#: 2499), in accordance with 45 CFR 46 regulations, also approved the study and determined it to be IRB-exempt. All participants provided written informed consent before participating in the study, ensuring their understanding of the purpose, procedures, and potential risks involved. Additionally, participants were informed that their responses would be anonymous and used solely for research purposes. No identifying information was collected or included in the manuscript to maintain confidentiality. There are no data involved in the submission that may identify an individual or groups of individuals.

Conflict of Interest Statement

Dr. Mostaghimi has received consulting fees from AbbVie, ACOM Health, Bioniz, Boehringer Ingelheim, Concert, Digital Diagnostics, Eli Lilly, Equillium, Hims & Hers Health, and Pfizer; equity from ACOM Health, Figure 1, and Hims & Hers Health; licensing/royalties from Concert and Pfizer; and research funding from Aclaris, Concert, Eli Lilly, and Incyte. Other authors have no conflicts of interest to disclose.

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Author Contributions

Katherine Sanchez, Ursula Biba, Samantha Gregoire, Lana Salloum, and Arash Mostaghimi conceptualized the study design, conducted the data analysis, and drafted the manuscript. Natasha Mesinkovska, Monique Margaret Waldman, and Lisa Anderson performed data collection, provided critical feedback, and revised the manuscript. All authors have read and approved the final version of the manuscript, contributed significantly to this work, and agreed to be accountable for all aspects of the work.

Data Availability Statement

The data analyzed in this study were obtained from a 2023 survey conducted by NAAF. These data are not publicly available due to ethical considerations and participant confidentiality. Researchers interested in accessing the data may submit a formal request to NAAF, which will evaluate access on a case-by-case basis in accordance with its data-sharing policies and applicable ethical guidelines. Further inquiries can be directed to the corresponding author.

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