Trends in Prevalence and Incidence of Alopecia Areata, Alopecia Totalis, and Alopecia Universalis Among Adults and Children in a US Employer-Sponsored Insured Population

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IMPORTANCE Alopecia areata (AA) is characterized by nonscarring hair loss of the scalp, face, and/or body. Alopecia totalis (AT) and alopecia universalis (AU) involve complete loss of the scalp and body hair, respectively. The epidemiology of AA in the US remains unclear, having previously been extrapolated from older studies that were limited to specific geographic areas or clinical settings, or from self-reported data.

OBJECTIVE To estimate the annual prevalence and incidence of AA and AT and/or AU (AT/AU) in the US.

DESIGN, SETTING, AND PARTICIPANTS This retrospective, population-based cohort study was conducted from January 2016 to December 2019 and included enrollees in the IBM MarketScan Commercial Claims and Encounters and Medicare Supplemental databases and their dependents, with plan enrollment during each study calendar year and the year prior.

EXPOSURES Prevalent cases were identified by 1 or more claims for AA or AT/AU (International Statistical Classification of Diseases, Tenth Revision, Clinical Modification [ICD-10-CM] codes L63.x, L63.0, L63.1) during each year of interest or the year prior. Incident cases were identified by 1 or more claims for AA or AT/AU during a specific year and no diagnosis the year prior.

MAIN OUTCOMES AND MEASURES Annual incidence and prevalence rates were calculated and stratified by age, sex, and region. National employer-sponsored insurance population estimates were obtained using population-based weights.

RESULTS Among eligible patients (2016: n = 18,368 [mean (SD) age, 40.6 (17.9) years; 12,295 women (66.9%)]; 2017: n = 14,372 [mean (SD) age, 39.6 (17.7) years; 9,195 women (64.0%)]; 2018: n = 14,231 [mean (SD) age, 38.9 (17.3) years; 8,998 women (63.2%)]; 2019: n = 13,455 [mean (SD) age, 39.1 (17.4) years; 8,322 women (61.9%)]), AA prevalence increased from 0.199% (95% CI, 0.198%-0.200%) in 2016 to 0.222% (95% CI, 0.221%-0.223%) in 2019. Roughly 5% to 10% of prevalent and incident cases of AA were AT/AU. The prevalence of AT/AU increased from 0.199% (95% CI, 0.198%-0.200%) in 2016 to 0.222% (95% CI, 0.221%-0.223%) in 2019. Incidence of AA per 100,000 person-years ranged from 87.39 (95% CI, 86.84-87.96) in 2017 to 92.90 (95% CI, 92.35-93.45) in 2019. Incidence of AT/AU ranged from 7.09 (95% CI, 6.94-7.25) in 2017 to 8.92 (95% CI, 8.75-9.09) in 2016.

Prevalence and incidence of AA and AT/AU were higher among female vs male individuals, adults vs children and adolescents, and in the Northeast vs other regions.

CONCLUSIONS AND RELEVANCE The results of this cohort study suggest that these recent AA prevalence and incidence estimates could help improve current understanding of the disease burden. Further research is warranted to elucidate subpopulation differences and trends in AA in the broader US population.

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Alopecia areata (AA) is an autoimmune disease characterized by nonscarring hair loss involving the scalp, face, and/or body. The most common forms of AA include small patches of hair loss, complete loss of scalp hair (ie, alopecia totalis [AT]), or complete loss of scalp, facial, and body hair (ie, alopecia universalis [AU]). While AA affects both sexes and all age groups, the first onset reportedly occurs by age 40 years in more than 80% of patients and by age 20 years in 40%. Although many patients with AA recover within the first year, an estimated 4.5% to 36.1% of patients may ultimately progress to develop AT and/or AU (AT/AU). Living with AA can be associated with reduced quality of life, social functioning, and psychological well-being, with substantial costs to patients and health care systems.

Despite the high burden of disease experienced by patients with AA, to our knowledge, evidence regarding the epidemiology of AA and AT/AU in the US remains limited. Existing estimates of the prevalence and incidence of AA have generally been extrapolated from older studies that were regionally based or conducted in specific clinical settings. The overall prevalence of AA was first estimated at 0.1% to 0.2% in the US based on the 1971 to 1974 First National Health and Nutrition Examination Survey. The lifetime incidence risk of AA in the US was estimated at 1.7% and 2.1% by the Rochester Epidemiology Project based on data from 1975 to 1989 and 1990 to 2009, respectively. However, these incidence rates (IRs) may not be representative of the general US population, as the data were restricted to Olmstead County, Minnesota, and only captured patients who were assessed and received their diagnosis in a clinical setting, primarily by dermatologists. Patients with AA are commonly encountered in clinical settings, comprising about 0.6% to 2.0% of new cases in dermatology clinics in the UK and US. Similarly, hospital-based studies worldwide have estimated the incidence risk of AA to be between 0.57% to 3.8%. To ascertain the epidemiology of AA in the broader community, a recent study conducted in 2020 reported the prevalence of AA and AT/AU in a large representative sample of the general US population using a 2017 online cross-sectional survey and clinician adjudication. Although the self-reported (0.04%) and clinician-adjudicated prevalence estimates for AT/AU were similar (0.04%), a considerable difference was observed regarding the clinician-adjudicated (0.21%) and self-reported (1.14%) prevalence of AA overall. In light of this evidence, further population-based studies using alternative approaches, such as insurance claims-based analyses, could help to develop annualized estimates of real-world prevalence and incidence and evaluate differences among subgroups of interest. Accordingly, the present study aimed to provide recent estimates of the annual and point prevalence and incidence of AA and AT/AU by sex, age group, and geographic region using a nationally weighted population from a large, nationwide US employer-sponsored insurance (ESI) claims database.

Methods

Data Source
This study used data from the IBM MarketScan Commercial and Medicare Supplemental databases from January 1, 2015, to December 31, 2019. These databases comprise more than 130 different insurance providers and third-party administrators in the US for more than 25 million patients annually. The data represent the demographic information and medical claims of insured active employees, dependents, early retirees, and consolidated omnibus budget reconciliation act beneficiaries from more than 40 national employers, as well as Medicare-eligible retirees with employer-provided Medicare Supplemental plans. Enrollment history and claims for medical (clinician and institutional) and outpatient pharmacy services are included, and inpatient service records are available at the claim and summarized stay levels. Given that data are deidentified and comply with the patient confidentiality requirements of the Health Insurance Portability and Accountability Act of 1996, this study was exempt from ethics review.

Study Design and Patient Selection
A retrospective, longitudinal cohort study design was used to estimate the annual prevalence rates (PRs) and IRs for AA and AT/AU during the analysis period spanning from 2016 to 2019 (Figure 1; eMethods and eTable 1 in Supplement 1). The study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines. The study population included all commercially insured US
individuals with AA and AT/AU who were identified using the International Statistical Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) code L63.x. Diagnoses of AT/AU were imputed forward within each patient based on the presence of at least 1 claim with a diagnosis of AT or AU during the data period available after the first AT/AU diagnosis. Specifically, if a patient had at least 1 diagnosis for AT or AU, all other AA diagnoses for that patient occurring after the first AT or AU diagnosis were considered to be AT/AU, which was consistent with previously published approaches.

Measures and Outcomes

Prevalence and Incidence

For annual prevalence and incidence estimation, all patients had to be continuously enrolled in a health insurance plan for the entire year of analysis and the year prior. If a patient was born during the year of analysis or the year prior, continuous enrollment was required from birth. If the first AA or AT/AU diagnosis occurred after the year of analysis, then the patient was not counted as either a prevalent or incident case for the year of analysis. The number of individuals in the population considered for each annual prevalence estimate (the denominator of the estimate) included all enrollees with continuous health insurance plan coverage from January 1 or birth (whichever came later) to December 31 during the year of analysis and year prior. The number of patients with AA or AT/AU in a given year of analysis, respectively (the numerator of the estimate), was calculated based on the number of patients with 1 or more inpatient (IP) or outpatient (OP) diagnosis codes for AA or AT/AU during the calendar year of analysis or year prior. Individuals in the at-risk population for each annual incidence estimate (the denominator of the estimate) included those with no diagnosis code for AA or AT/AU during the year prior, which served as the washout period. Among the at-risk population, the number of incident patients in a given year of analysis (the numerator of the estimate) included those with 1 or more IP or OP claims with a diagnosis code for AA or AT/AU during the year of analysis but not the year prior. In addition to the annualized estimates described previously, point prevalence was calculated as the number of patients who had at least 1 IP or OP claim with a diagnosis for AA or AT/AU during the 12 months before July 1 of the year of analysis divided by the number of patients who were continuously enrolled during that period.

The crude annual PR for AA and AT/AU was estimated as the number of individuals with AA or AT/AU, respectively, divided by the total number of patients covered in the year of analysis and year prior. Nationally weighted annual PRs were obtained using weights calculated based on data from the American Community Survey, which contains information on census division, age, sex, and policy holder status. Crude annual IRs for AA and AT/AU were estimated based on the number of individuals with newly diagnosed AA or AT/AU, respectively, divided by the total number of individuals at risk. Nationally weighted annual IRs were obtained using the same method as described previously.

Annual PRs were expressed as the percentage of prevalent patients in a given year of analysis, and annual IRs were expressed as patients with a new diagnosis per 100 000 person-years (PYs). The 95% CIs were calculated using the Wilson binomial interval approach for weighted annual PRs and the Poisson exact approach for weighted annual IRs.

Patient Characteristics

Patient characteristics were summarized among newly diagnosed cases for each calendar year of analysis from 2016 to 2019. Demographic and clinical characteristics were measured at the earliest incident AA diagnosis date in the year of interest. Presence of comorbidities was evaluated using data from the full calendar year. Patient characteristics among annual incident cases were described using means and standard deviations for continuous variables and frequencies and proportions for categorical variables.

Statistical Analysis

In addition to the descriptive analyses described previously, a trends analysis was conducted to estimate temporal changes in annual PR among the overall study sample and stratified by sex (female and male), geographic region (Northeast, Midwest, South, and West), and age group. Specifically, the annual PR during each subsequent calendar year was compared with the annual PR in 2016 using weighted logistic regression models, and changes in annual IRs from 2016 onward were estimated using weighted Poisson regression models. Significance was assessed at an α level of P < .05. All statistical analyses were performed using SAS, version 9.4 (SAS Institute), and R, version 3.6 (R Foundation).

Results

Annual Prevalence and Incidence in the Overall Population

In the overall study population weighted to the US ESI population, the annual prevalence of AA increased slightly from 2016 to 2019. Prevalence rates of AA increased slightly from 0.199% in 2016 to 0.222% in 2019. The annual prevalence rates of AT/AU were 0.012% in 2016 and appeared to increase to 0.019% by 2019, respectively. In the overall study population, the annual incidence of AA per 100 000 PYs was 91.46 in 2016, 87.39 in 2017, 91.32 in 2018 (P = .73), and 92.90 in 2019. The annual incidence of AT/AU per 100 000 PYs ranged between 7.09 in 2017 and 8.92 in 2016.

Annual Prevalence and Incidence by Subgroup

Prevalence rates of AA were higher among female (95% CI, 0.252%-0.271%) vs male individuals (0.145%-0.171%) regardless of age, although this sex difference was more pronounced among adults than in children and adolescents (Figure 2). Prevalence was also higher among adults (range, 0.220%-0.245%) vs children and adolescents (range, 0.120%-0.135%) and in the Northeast (range, 0.273%-0.305%) vs other regions (range, 0.155%-0.222%). Among children and adolescents (Figure 2A), the annual prevalence of AA was highest among adolescents aged 12 to 17 years (range, 0.149%-0.165%) and lowest among those aged 0 to 5 years (range, 0.067%-0.072%). Among adults (Figure 2B), the highest annual prevalence of AA was observed among individuals aged...
18 to 44 years (range, 0.254%-0.278%) and the lowest among those 65 years or older (range, 0.150%-0.167%). Similar results were observed for the annual prevalence of AT/AU among age-related subgroups of children and adolescents and adults (Figure 2, C and D).

The subgroup analysis of AA incidence yielded a pattern consistent with AA prevalence. Specifically, rates were higher among female (range, 108.53-118.56) vs male individuals (range, 63.68-72.09), adults (range, 95.45-102.63) vs children (range, 56.08-60.05), and in the Northeast (range, 116.95-124.21) vs other regions (range, 67.16-97.12). Likewise, the annual incidence of AA per 100,000 PYs in children and adolescents was highest among individuals aged 12 to 17 years (range, 65.83-63.29; Figure 3A) while the incidence among adults was highest in those aged 18 to 44 years (range, 117.06-119.14; Figure 3B). The incidence of AT/AU by age-related subgroups of children and adolescents and adults followed a similar pattern to that of AA (Figure 3, C and D). A similar sex-related pattern was observed for the annual incidence of AA and AT/AU (Figure 3, A and D), with higher rates among female individuals.

**Patient Characteristics**

Overall, patient characteristics of incident cases were similar during the analysis period (Table 2). On average, patients received a diagnosis of AA at the mean (SD) age of between 38.9 (17.3) (2018) to 40.6 (17.9) years (2016). Approximately 8322 (61.9%) (2019) to 12295 (66.9%) (2016) of the patients were female, and between 5485 (38.5%) (2018) and 7979 patients (43.4%) (2017) lived in the South. Between 1063 (7.5%) and 1694 patients (9.2%) had AT/AU subtype, and between 7536 (53.0%) (2018) and 7941 patients (55.3%) (2017) with AA or AT/AU first received their diagnosis from a dermatologist. Mean Charlson Comorbidity Index score values and rates of other co-morbidities were also relatively similar across years.

**Discussion**

In a large, nationally representative population of commercially insured patients in the US, the number of prevalent and incident AA and AT/AU cases appeared to increase slightly from...
2016 to 2019 in the US. Overall, the prevalence and incidence of AA and AT/AU were higher among female vs male individuals, adults vs children and adolescents, and in the Northeast vs other regions. An estimated 7.5% to 9.2% of prevalent and incident cases of AA were AT/AU. The prevalence and incidence of AA appeared to increase in adolescence (ie, age 12-17 years) and reach a peak in young adulthood (ie, age 18-44 years), with higher rates observed among female individuals regardless of age group.

Alopecia Areata Prevalence Rates
The present study found similar AA PRs (0.199%-0.222% from 2016-2019) to the clinician-adjudicated prevalence rate (0.210% in 2017) reported by a recent survey study, which is consistent with earlier estimates from the First National Health and Nutrition Examination Survey (0.1%-0.2% from 1971-1974). The self-reported rate of AA in the survey study (1.14% in 2017), which accounts for those patients not seeking medical care, suggests that the true prevalence of AA in the community might be higher than reported from medical claims. In the present study, AT/AU PRs (0.012%-0.019% from 2016-2019) were found to be lower than the rate reported in the survey study (0.040% in 2017, respectively). Since the current study estimated prevalence in a population of patients seeking care when no approved treatments were available, these rates may be understating the true AT/AU prevalence, particularly in light of prior research that found AT/AU codes may be underused by clinicians. With the recent approval of baricitinib by the US Food and Drug Administration as a treatment for AA and other treatments currently in development, more patients with AA may seek treatment and thus get a clinical diagnosis from health care clinicians, which would plausibly increase the incidence and prevalence rates of AA based on claims data. However, this trend may be contingent on the overall safety of the new treatments, as well as their coverage by payers, which is critical to patient access.

The annual incidence of AA in the present study (91.46-92.90 cases per 100 000 PYs from 2016-2019) appeared higher than previous estimates from the Rochester Epidemiology Proj-
Table. Patient Characteristics of the Incidence Cohort From 2016 to 2019

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of patients</td>
<td>18,368 14,372 14,231 13,455</td>
</tr>
<tr>
<td>Demographic and clinical</td>
<td></td>
</tr>
<tr>
<td>Age, mean (SD), y</td>
<td>40.6 (17.9) 39.6 (17.7) 38.9 (17.3) 39.1 (17.4)</td>
</tr>
<tr>
<td>Female</td>
<td>12,295 (66.9) 9,195 (64.0) 8,998 (63.2) 8,322 (61.9)</td>
</tr>
<tr>
<td>Male</td>
<td>6,073 (33.1) 5,177 (36.0) 5,374 (36.8) 5,133 (38.1)</td>
</tr>
<tr>
<td>Geographic region</td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>4,455 (24.3) 3,522 (24.5) 4,027 (28.3) 3,857 (28.7)</td>
</tr>
<tr>
<td>Midwest</td>
<td>3,034 (16.5) 2,376 (16.5) 2,437 (17.1) 2,371 (17.6)</td>
</tr>
<tr>
<td>South</td>
<td>7,979 (43.4) 6,101 (42.5) 5,485 (38.5) 5,262 (39.1)</td>
</tr>
<tr>
<td>West</td>
<td>2,900 (15.8) 2,373 (16.5) 2,282 (16.0) 1,965 (14.6)</td>
</tr>
<tr>
<td>Insurance type</td>
<td></td>
</tr>
<tr>
<td>Managed care*</td>
<td>14,334 (78.0) 10,774 (75.0) 10,813 (76.0) 10,169 (75.6)</td>
</tr>
<tr>
<td>Consumer driven*</td>
<td>3,227 (17.6) 2,930 (20.4) 2,834 (19.9) 2,818 (20.9)</td>
</tr>
<tr>
<td>Comprehensive</td>
<td>710 (3.9) 550 (3.8) 466 (3.3) 373 (2.8)</td>
</tr>
<tr>
<td>Type of AA</td>
<td></td>
</tr>
<tr>
<td>AT/AU</td>
<td>1,694 (9.2) 1,114 (7.8) 1,063 (7.5) 1,069 (7.9)</td>
</tr>
<tr>
<td>Non-AT/AU</td>
<td>16,674 (90.8) 13,258 (92.2) 13,168 (92.5) 12,386 (92.1)</td>
</tr>
<tr>
<td>First diagnosis by dermatologist</td>
<td>9,916 (54.0) 7,941 (55.3) 7,536 (53.0) 7,242 (53.8)</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
</tr>
<tr>
<td>Any atopic comorbidities#</td>
<td>3,886 (21.2) 3,127 (21.8) 3,226 (22.7) 2,930 (21.8)</td>
</tr>
<tr>
<td>Any autoimmune comorbidities#</td>
<td>2,948 (16.0) 2,203 (15.3) 2,230 (15.7) 2,092 (15.5)</td>
</tr>
<tr>
<td>Charlson Comorbidity Index score, mean (SD)$$</td>
<td>0.4 (0.9) 0.3 (0.9) 0.4 (0.9) 0.3 (0.9)</td>
</tr>
</tbody>
</table>

Abbreviations: AA, alopecia areata; AT, alopecia totalis; AU, alopecia universalis.

* Composite of health maintenance organization, preferred clinician organization, point of service, and exclusive clinician organization plans.

# Composite of consumer-driven health plans and high-deductible health plans.

$ Composite of allergic rhinitis, asthma, atopic dermatitis, celiac disease, chronic urticaria, and conjunctivitis.

$$ Composite of ankylosing spondylitis, Crohn disease, diabetes mellitus, Hashimoto disease, systemic lupus erythematosus, psoriasis, rheumatoid arthritis, Sjögren syndrome, ulcerative colitis, and vitiligo.

Limitations

The present study had limitations. First, coding inaccuracies or data omissions may have been associated with misidentification of patients with AA and AT/AU. Moreover, we could not discern AA rates by degree of scalp hair loss (outside of AT/AU) as this information was unavailable in claims data. Second, the generalizability of the study findings beyond patients with commercial or Medicare supplemental insurance may be limited. Although the current sample was weighted to the US ESI population, we could not control for all potential differences in patient characteristics between our study sample and the general US population. Furthermore, since the present data are limited to patients actively utilizing health care resources for AA, the calculated IRs and PRs might be underestimates. Due to a lack of race and ethnicity information in the claims database, we were not able to calculate incidence and prevalence rates for racial and ethnic subgroups. Finally,
despite the 12-month washout period used for identifying incident cases, some of these patients may have received their diagnoses before the data period and were prevalent cases. However, a sensitivity analysis requiring at least 2 claims with AA diagnoses revealed lower incidence and prevalence rates (eTable 2 in Supplement 1) in agreement with prior literature that AA is transient in some cases.37

Conclusions

Evidence regarding the epidemiology of AA and AT/AU in the US remains limited, despite a known clinical, economic, and humanistic burden of disease.2,8-15 Using recent data from a large, nationally representative US ESI population, this population-based cohort study found that AA prevalence was within the range of clinician-adjudicated estimates for the general US population,21 while AA incidence was higher than previous estimates obtained in US clinical settings.5,16 A slight increase in the number of existing and newly diagnosed AA and AT/AU cases from 2016 to 2019 could indicate a growing burden of disease or may reflect an increasing proportion of patients seeking care, with a more pronounced burden among female individuals, adults, and residents of the Northeast. Taken together, this study highlights contemporary trends in the annual prevalence and incidence of AA and AT/AU over time among a large, real-world US population, which may help to inform future analyses of the burden of disease.

ARTICLE INFORMATION

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Author Contributions: Drs Done and Gao had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Mostaghimi, Gao, Ray, Wang, Carley, Done, Swallow.

Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: Gao, Ray, Bartolome, Wang, Carley, Done.

Critical revision of the manuscript for important intellectual content: Mostaghimi, Gao, Ray, Bartolome, Wang, Done, Swallow.

Statistical analysis: Gao, Ray, Wang, Cartley, Done.

Obtained funding: Ray.

Administrative, technical, or material support: Mostaghimi, Ray, Bartolome, Wang, Done.

Supervision: Mostaghimi, Gao, Ray, Bartolome, Done, Swallow.

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REFERENCES


