

Burden of Illness in Alopecia Areata: A Cross-Sectional Online Survey Study



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Previous QOL and disease burden studies have not captured all relevant aspects of living with alopecia areata (AA). To better understand the burden and everyday experience of living with moderate-to-severe AA, a cross-sectional, online, quantitative-qualitative survey was developed to assess symptoms, relationships, productivity, treatments, and financial burden. Adult patients were recruited from the National Alopecia Areata Foundation database. Data were analyzed descriptively. A total of 216 patients completed the survey. Most were female (83%), aged ≥ 45 years (59%), and white (78%). Nearly 2 of 3 respondents (62%) made different major life decisions (regarding relationships, education, or career) owing to AA. Most respondents (85%) stated coping with AA as a daily challenge, citing mental health issues, concealing hair loss, and others' reactions; 47% reported anxiety and/or depression. Many patients (75%) persistently concealed hair loss (mean time spent, 10.3 h/wk). Treatment discontinuation was common owing to lack of efficacy, side effects, and cost. Associated expenditures included buying wigs or hairpieces and psychotherapy (mean \sim \$2,000/y each). Survey respondents comprised a self-selected sample, which may not reflect the entire population. The impact of AA extends beyond cosmetic concerns and carries a considerable psychosocial burden. Efficacious, less burdensome AA treatments are needed to regrow hair and alleviate psychosocial sequelae.

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INTRODUCTION

Alopecia areata (AA) is an autoimmune disease characterized by nonscarring hair loss and is currently estimated to affect approximately 6.8 million people in the United States (National Alopecia Areata Foundation, 2019; Pratt et al., 2017). Hair loss may be limited to patches of the scalp, although any hair-bearing site (e.g., eyebrows, eyelashes, beard), the entire scalp, or the entire body may be affected (Hordinsky, 2013; Villasante Fricke and Miteva, 2015). The age of onset varies, but AA generally occurs in patients aged < 40 years (Pratt et al., 2017; Villasante Fricke and Miteva, 2015).

Medical management of AA is difficult, and available treatment options have had limited success (Delamere et al., 2008; Hordinsky, 2013; MacLean and Tidman, 2013; Shapiro, 2013). Many patients rely on the use of alternative and/or complementary medicines and wigs or other concealments when drug treatments fail (Montgomery et al., 2017). Recent advances in understanding disease pathogenesis have resulted in new treatment approaches; in particular, Jak inhibitors have shown promise in promoting hair regrowth (Phan and Sebaratnam, 2019; Xing et al., 2014).

Although AA treatments are primarily designed to promote hair regrowth, studies have shown that the condition is also associated with significant psychological distress. Depression, anxiety, sleep problems, and suicide are more prevalent in patients with AA compared with the general population (Bilgiç et al., 2014; Cash, 2001; Layegh et al., 2010; Miller et al., 2015; Sinclair, 2014; Vallerand et al., 2019); however, descriptive data about the psychosocial effects of living with AA are scarce. Previous QOL and disease burden studies have used a combination of generic- and disease-specific patient-reported outcome measures (Finlay et al., 2012; Grob et al., 1999; Leary, 1983; Mendoza et al., 2013; Rand Corporation, 2018; Shi et al., 2013), and although validated, these tools do not capture in detail all aspects of day-to-day living that may be relevant to this patient population and thus do not reflect the total impact of the disease on patients living with AA. Previous research has also been conducted in broad patient populations with AA and has not specifically examined the moderate-to-severe disease subpopulation.

To address these knowledge gaps, an online survey was conducted to assess the burden of disease associated with self-reported moderate-to-severe AA.

RESULTS

Demographics, physical symptoms, and comorbidities

A total of 216 eligible respondents completed the survey (Table 1). Patients had a median disease duration of 13 years (range, < 1 –60 years). Most patients (77%) self-reported their hair loss as being severe, with hair loss affecting more than one-third of their scalp (78%). Nearly one-quarter of respondents (22%) had hair loss on less than one-third of their scalp, but self-reported their condition as being moderate or severe.

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Abbreviation: AA, alopecia areata

Table 1. Demographic Characteristics of Study Population

Characteristics	Survey Respondents (N = 216)
Sex, n (%)	
Male	39 (18)
Female	177 (82)
Age, y	
Mean	46.9
Median	47
Range	18–82
Age grouping, y, n (%)	
18–25	23 (11)
26–35	31 (14)
36–45	46 (21)
46–55	54 (25)
55–65	32 (15)
>65	30 (14)
Geographic region, n (%)	
North	29 (13)
East Coast	61 (28)
Midwest	37 (17)
South	42 (20)
West	47 (22)
Race or ethnicity, n (%)	
White	168 (78)
Black or African American	14 (6)
Mixed race	13 (6)
Other	9 (4)
Asian	7 (3)
Prefer not to say	4 (2)
American Indian or Alaska Native	1 (<1)
Marital status, n (%)	
Never married or single	60 (28)
Married or civil partnership	115 (53)
Divorced	31 (14)
Widowed	5 (2)
Prefer not to say	5 (2)
Education, n (%)	
Non-graduate	0 (0)
High school graduate	59 (27)
College graduate	75 (35)
Advanced degree	79 (37)
Prefer not to say	3 (1)
Employment status, n (%)	
Full-time	125 (58)
Retired	31 (14)
Part-time	25 (12)
Unemployed	10 (5)
Student	9 (4)
Other	9 (4)
Unable to work (disability)	4 (2)
Prefer not to say	3 (1)
Annual household income (pre-tax), \$, n (%)	
<25,000	22 (10)
25,000–34,999	20 (9)
35,000–49,999	22 (10)
50,000–74,999	34 (16)
75,000–99,999	24 (11)
100,000–149,999	35 (16)
150,000–199,999	18 (8)
>200,000	13 (6)
Prefer not to say	28 (13)

Hair loss was experienced beyond the scalp, including the face and body. Complications related to loss of eyebrows (74% of patients) and eyelashes (68%) included sweat, water, and debris in the eyes; with loss of nasal hair (50%), frequent runny nose and sneezing; and with hair loss on the scalp (100%), sensitivity to temperature and sunburn. Nail symptoms (51%) included splitting and discoloration.

Most respondents (85%) reported ≥ 1 comorbidity, the most common being anxiety and/or depression (47%). Rates of anxiety and/or depression were higher in women and younger patients. Other common comorbidities included atopic disorders: allergic rhinitis (35%), thyroid disease (30%), atopic dermatitis (19%), and asthma (13%).

Psychosocial impact

Nearly two-thirds of respondents (62%) agreed they had made different major life decisions (regarding relationships, education, or career) as a result of AA. Coping with AA was reported as a daily challenge for 85% of respondents and included worries that others will not find them attractive (78%), feeling anxious in social situations (69%), being treated differently by others (58%), and worries about hair regrowth (56%). Respondents reported the highest impact of AA on daily life was on self-esteem or confidence (Figure 1). Qualitatively, patients described feelings of insecurity and low self-esteem that were associated with relationship breakdown and impaired performance at work or school (Table 2).

Low self-esteem

In qualitative responses, patients described feeling ashamed, humiliated, and profoundly depressed as a result of hair loss. A total of 71% of patients reported that AA had a marked impact on their self-esteem and that this impact did not abate over time. Hair loss was closely linked to a sense of changing self-identity, and for many respondents, getting used to an altered appearance was described as devastating and emotionally draining. Being unable to look at themselves in the mirror was a recurring theme.

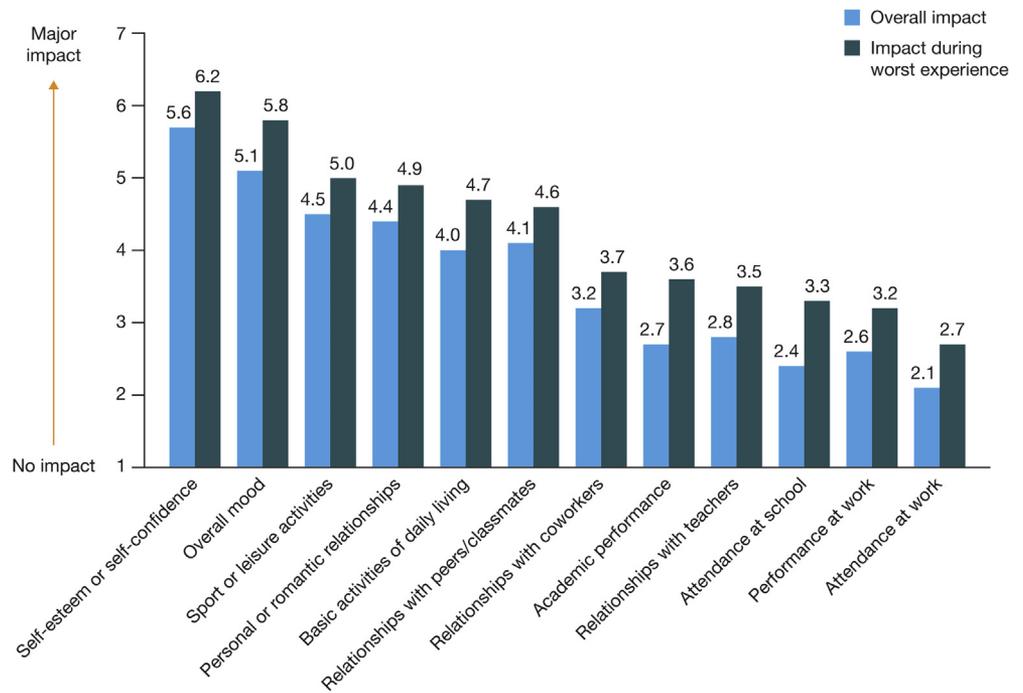
Relationships (romantic)

AA was described as an impediment to developing new relationships. Patients reported not knowing how to speak to new partners about AA and worry that potential partners would find them unattractive. Patients also reported problems in existing relationships, citing feelings of insecurity about appearance, which was often related to decreased intimacy. Almost one-third of patients (31%) reported the end of a relationship because of AA (partners were unable to accept or cope with hair loss and changed appearance).

Relationships (friends and family)

Social withdrawal is common in AA, especially at disease onset. Patients reported withdrawing from activities (62%) and reducing interactions with friends (54%) after the first episode of hair loss. Respondents reported feeling isolated, bullied, and rejected socially because of AA. Explaining AA to their children was also identified as a challenge; children were described as being distressed by the change in their parent's appearance and concerned that similar sudden hair loss could also happen to them. Respondents who experienced AA in childhood reported feeling that their parents

Figure 1. Impact of AA on everyday life—mean response (N = 216).
 QC4: Since your diagnosis, how would you rate the overall impact of your alopecia areata on the following aspects of your life? Please select the rating that best matches the impact, using the scale below: 1 = no impact; 4 = some impact; 7 = major impact.
 QC8b: Thinking about the time in your life when your alopecia areata was at its worst, please rate the impact this had on your overall day-to-day living at that time: 1 = no impact; 4 = some impact; 7 = major impact.
 AA, alopecia areata; QC, question (section C).



were disappointed in the change in their appearance. Respondents also reported annoyance at having to explain to others that they do not have cancer or another serious condition responsible for hair loss.

Education and career

Of the patients attending school (n = 47), 51% reported missing time from school because of AA. Patients reported performing poorly because of distraction and distress associated with their AA, including failing, having to repeat academic years, and discontinuing education.

Many patients described negative effects on their professional lives. Of the 61% of employed patients (n = 132), 45% reported missing time from their job because of AA. Some resigned from their positions, citing stress from having to wear a wig at work or unsupportive reactions of coworkers. Resignations were followed by financial struggles. Patients also suggested that promotions had been hampered by poor self-esteem and negative reactions from colleagues. Some reported being unable to find employment owing to a lack of self-esteem and confidence.

Making adjustments

The survey defined adjustments as modifications undertaken as a result of AA. After the first symptoms, 93% of respondents reported making ≥1 adjustment, whereas 87% continued to make ≥1 adjustment consistently (Figure 2). Over time, the frequency of social withdrawal decreased, whereas adjustments to conceal hair loss or alter appearance remained fairly constant. Among women, 90% reported concealing hair loss at first symptoms, and 84% continued to conceal their hair loss, compared with 72% and 38% of men, respectively.

Concealment strategies such as wigs or weaves and cosmetic procedures resulted in substantial financial and

time burdens. Most patients (75%) indicated that their medical insurance does not cover the cost of concealment and that out-of-pocket costs can amount to thousands of dollars per year. The mean estimated cost of wig or weave or hairpiece was \$2,211/y (n = 112). The current mean estimated time spent concealing hair loss was 10.3 h/wk, increasing to 13.7 h/wk when AA was at its worst.

Current use of some form of concealment (e.g., hats, wigs, makeup) was reported by 31–65% of patients, and most did not discontinue concealments over time. Although over one-half of respondents indicated currently wearing a wig or hairpiece, many described them as highly unsatisfactory: hot, expensive, uncomfortable, and not looking like real hair.

Treatment

Respondents consulted many health care professionals to manage different aspects of their AA, including dermatologists (89%), primary care physicians (61%), psychological or behavioral health specialists (23%), hair loss specialists (22%), rheumatologists (13%), and pharmacists (12%).

Patients used a wide range of medical treatments, the most common of which were intralesional steroid injections, topical steroids, and topical minoxidil (Figure 3). Except for dietary and/or herbal supplements, the use of treatment declined from diagnosis to present day; discontinuation of treatment was most common owing to side effects and lack of efficacy. Patients described their treatment experience as highly unsatisfactory.

About half of the patients (49%) reported having insurance coverage for treatment. Patients without insurance coverage indicated that the cost of treatment was a barrier. The highest mean cost for patients was for counseling and/or therapy at \$1,961/y. The mean time spent attending therapy was reported by 23 patients to be 1.5 h/wk at the time of survey completion and 3.8 h/wk when their AA was at its worst.

Table 2. Select Responses to Open-Ended Questions About the Impact of AA on Daily Living

Questions

QC1: Thinking back to when you were first diagnosed with alopecia areata, what would you say were the biggest challenges you faced / had to deal with?

QC6: Thinking about your experience with alopecia areata, are there any other areas of your life that have been impacted which have not been covered in the questions above? If so, please provide more detail using the space below.

QC7: Thinking about now and your recent past, what would you say is the biggest challenge you face as someone with alopecia areata?

QC8a: Please think about the time in your life in which you feel your alopecia areata was at its worst. Please describe how much hair loss you experienced, any symptoms you experienced or other effects of hair loss, and the impact this had on your life. Why was this your worst experience?

Responses

Self-esteem

"Severe, severe depression. Crying every time I look in the mirror."

"The biggest challenge was the hit to my self-esteem. It triggered a deep depression that seriously impacted me physically and mentally."

"It's a struggle to get out of bed every morning. I do not like looking in the mirror as I do not recognize the person looking back at me."

"It's very embarrassing. I feel ashamed and depressed."

"I went to so many dermatologists and they all told me the same story. They could not help me because there is no cure. I was very depressed, and isolated from everybody."

"It really affected my personality – I became harder and more closed off. I'd always been a pretty outgoing person."

Relationships (romantic)

"Recently, I'd say my biggest challenge was feeling attractive to someone who would be interested in a romantic relationship."

"One of the last things he said when he left me for another woman was 'why didn't you wear a wig when we had sex?'"

"Having to tell boyfriends that I have alopecia and hoping I wouldn't be rejected for being bald."

"Dating and making/maintaining friendships is the hardest."

"Worrying that my husband will stop finding me attractive (stop 'tolerating' my appearance)."

"My boyfriend had a hard time adjusting, so he began distancing himself from me, which made my self-esteem worse."

"Don't feel sexy or good about myself – don't want to have sex, not interested to get close."

Relationships (friends and family)

"I fell into an extreme depression which affected my ability to care for my children."

"I started skipping class a lot, became a hermit and stopped answering calls from friends."

"To explain autoimmune disease to terrified children desperate for assurances that nothing so horrifying will happen to them."

"Seeing my Dad's disappointment hurt me – thought he didn't love me."

"How would my fiancée ever look at me? Would my son be ashamed of me?"

School or work

"I looked different, was very insecure and an easy target to make fun of. That year I did have to stay back due to academic failure because I didn't attend school due to bullying."

"One of the kids pulled off my wig in school. I ran out and wouldn't return for a few years. I refused to go and my Mom had to obtain a tutor for me."

"I ditched class a lot – barely made it through. It hindered my ability to find a job or even enter a place. I was so shy and introverted, depressed and miserable."

"It has affected me financially. I quit my job because I couldn't handle the stress of wearing a wig all day."

"Trying to be taken seriously as a contender for promotion while patches of hair were dropping every day."

"I am having trouble getting a new job. I do not have confidence in myself like I did when I had my hair."

Abbreviation: QC, question (section C).

DISCUSSION

AA has a profound impact on patients' daily lives, extending far beyond cosmetic concerns. Notably, nearly one-fourth of respondents had hair loss affecting less than one-third of their scalp but reported their condition as moderate-to-severe.

Patients reported a range of physical symptoms and complications associated with AA, including sensitivity to

temperature and light, increased susceptibility to sunburn, nail splitting, dryness and irritation in eyes and nose, and inability to keep sweat and debris out of eyes.

Of 17 reported comorbidities, anxiety and/or depression was the most prevalent and was reported by nearly 50% of respondents. AA has had a major emotional impact on patients' daily lives, causing 62% of patients to report making

Figure 2. Adjustments made after first symptoms and currently (at survey completion) (N = 216). QC2a: What adjustments, if any, did you make once you first started experiencing symptoms of alopecia areata? QC2b: And which of these do you do today? QC, question (section C).

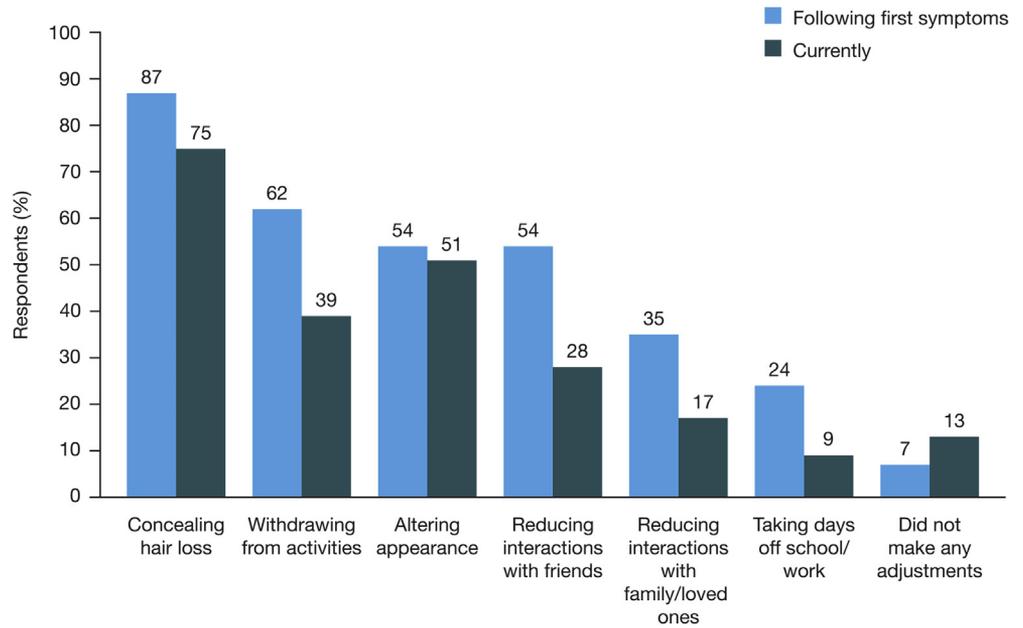
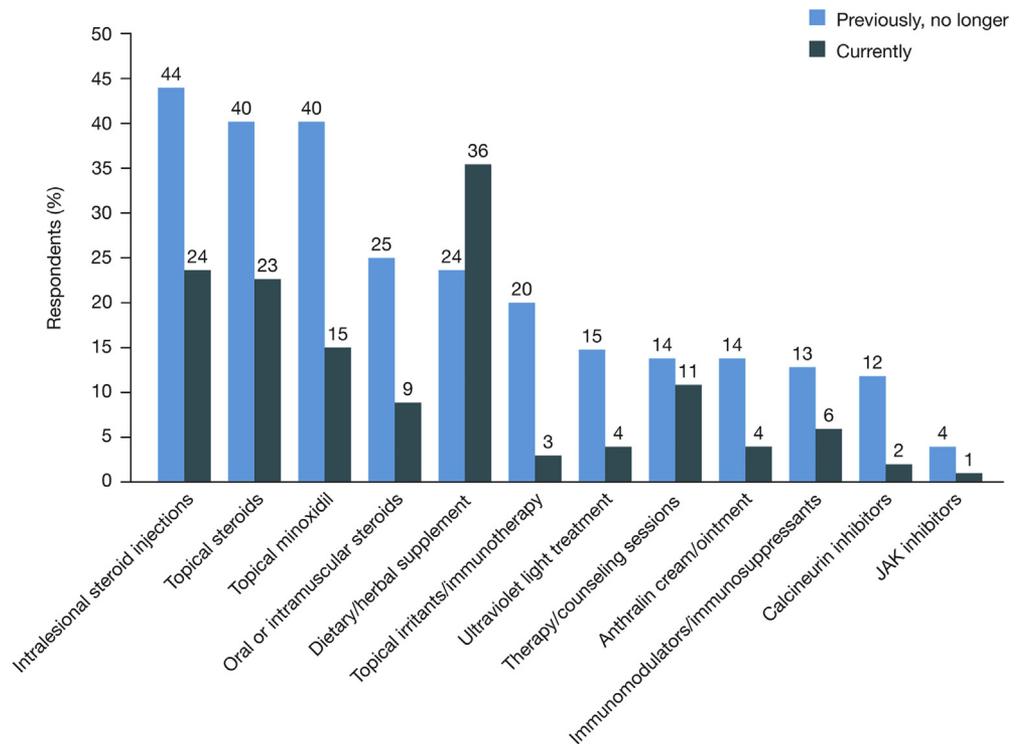


Figure 3. Treatments discontinued and currently used (N = 216). QD2: Which of the following treatments or concealers do you use to help you manage your alopecia areata? Please indicate if these are products you currently use or if these are products you have used in the past but no longer use. QD, question (section D).



decisions that negatively redirected the trajectory of their lives. As a result of emotional distress and loss of self-esteem caused by AA, patients have withdrawn from social interaction, performance has suffered at school and work, relationships have been broken, and careers stalled or lost. These qualitative results are supported by a recent study reporting that AA is associated with subsequent development of major depressive disorder; however, interestingly, this study also reported a

bidirectional association wherein depression was a risk factor for developing AA (Layegh et al., 2010).

Most respondents (85%) agreed that coping with AA is a daily challenge, and 87% continue to make adjustments in response to the disease. One of the most striking results from the survey is the substantial amount of time patients reported spending concealing hair loss, averaging 10.3 h/wk, up to 13.7 h/wk during periods of extensive hair loss,

translating into a period of 3–4 weeks of lost time per year. Although the use of wigs has been reported to increase confidence and reduce social anxiety (Montgomery et al., 2017), this is a substantial amount of time to spend in front of the mirror confronting an unrecognizable appearance, and patients also report worries related to others noticing their wig (Montgomery et al., 2017). In addition, insurance does not generally reimburse concealment strategies, requiring patients to cover the costs themselves. These results suggest that the majority of respondents have not come to terms with living with AA but continue to be at least inconvenienced and, at worst, distressed by the condition.

Patients reported seeking care from a wide range of practitioners and using many different therapies for different manifestations of their condition, often seeking cosmetic options or alternative treatments when conventional treatments failed to work. The use of treatments tended to decrease over time. Side effects and lack of efficacy were the most common reasons for treatment discontinuation. These results corroborate previous observations describing how patients disengage from the health care system and traditional treatments owing to lack of success (Hussain et al., 2017). Some patients reported frustration with the medical community, feeling their concerns related to the psychological and social impact of AA were dismissed. It should be noted that nearly 25% of patients have received psychological treatment, which, on the one hand, underscores the mental health burden associated with AA, but on the other hand, suggests there is a proportion of patients who remain untreated given the high prevalence of anxiety and/or depression.

The cost was also reported as a barrier by those without insurance. The two highest reported annual expenses linked to living with AA—wigs or hairpieces and psychotherapy—both correlate to coping with the psychosocial impact of the condition. In another survey of patients with AA, the majority (57%) reported the associated financial impact as moderately or severely burdensome, and patients' willingness to tap into savings or borrow money to cover out-of-pocket costs highlights and compounds the magnitude of the psychological impact of the disease (Li et al., 2019).

Achieving a greater understanding of unmet needs is particularly relevant as new therapies targeting AA autoimmune pathogenesis are investigated (Pratt et al., 2017; Renert-Yuval and Guttman-Yassky, 2017; Xing et al., 2014). In light of this survey's psychosocial findings, it will be important for treatment studies to explore outcomes beyond hair regrowth. Indeed, further investigation may be warranted to assess the hypothesis that the cumulative impact of AA-related psychosocial distress can alter life trajectory.

Although this survey sheds light on the impact of AA, the response rate was low, and these self-reported data may not be representative of the entire United States' patient population. The methodology may have biased the sample in favor of those who are computer literate and actively engaged with the National Alopecia Areata Foundation and the AA community. Although epidemiologic studies of AA report no significant differences in age, sex, race, or the age of onset, our sample favored white women aged over 45 years (17% of

respondents were male). In addition, the study did not include a control or comparator population, which makes it difficult to interpret some aspects of the results, such as the association of AA with anxiety and/or depression. Finally, because all survey data were collected anonymously, respondents were not contacted to clarify responses.

AA has a negative impact on many aspects of daily life, extending far beyond cosmetic concerns. Our results reveal a significant psychosocial impact that does not abate over time. AA can negatively redirect the course of a patient's life, culminating in unfulfilled professional and academic aspirations as well as diminished expectations for relationships and family life. Hair loss concealment techniques and treatments were considered unsatisfactory by patients with AA and imposed a significant time and financial burden. This survey highlights the need for efficacious, less burdensome treatments to promote hair regrowth, alleviate the psychosocial burden, and improve QOL for patients with AA.

MATERIALS AND METHODS

Participants and setting

Participants were recruited through email from the National Alopecia Areata Foundation patient database. The recruitment goal was 250 patients. The survey was administered from July to August 2018. Eligible participants were aged ≥ 18 years, United States' residents, and had a (self-reported) confirmed diagnosis of AA and either had (i) current hair loss involving at least one-third of the scalp area or (ii) hair loss involving less than one-third of the scalp and self-reported AA severity of moderate or severe. Consulting at McCann Health (New York, NY) conducted the study on behalf of the study sponsor, Concert Pharmaceuticals (Lexington, MA). Surveys were completed online and hosted by CobaltSky (London, United Kingdom).

Survey

The 30-minute, cross-sectional, quantitative-qualitative survey was developed based on a review of medical literature, findings from previous studies, and input from the authors, physician experts in AA. A pilot survey was conducted with five patients with AA who are Health and Research Ambassadors from the National Alopecia Areata Foundation; their feedback was used to improve ease of completion and enhance validity and clarity of content. Potential survey participants were asked to complete eight screening questions to determine eligibility. The 25-item survey consisted of four sections: (i) clinical severity and symptoms, (ii) impact on daily living and activities, (iii) financial and treatment burden, and (iv) demographics.

Patients provided informed consent to share their health data before participating in the study and could withdraw from the study at any time without penalty. No personally identifiable information was collected. The survey received approval from an independent Institutional Review Board (Pearl Institutional Review Board).

Statistical analysis

There was no single primary endpoint or total score for this study. Descriptive statistics were calculated for quantitative questions; no statistical comparisons were made between subgroups. Qualitative responses were organized into thematic categories and summarized.

Data availability statement

Datasets related to this article will be provided upon reasonable request submitted to the corresponding author.

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CONFLICT OF INTEREST

NM is the chief scientific officer of the National Alopecia Areata Foundation. JC is an employee of Concert Pharmaceuticals and reports receiving stock options and salary as part of his compensation. BK reported serving on advisory boards as a consultant and/or clinical trial investigator for Aclaris Therapeutics, Arena Pharmaceuticals, Bristol-Myers Squibb, Concert Pharmaceuticals, Dermavant Sciences, Eli Lilly and Company, Pfizer, and Viela Bio; and being on speakers bureaus for Pfizer, Regeneron, and Sanofi Genzyme. PM reported being a clinical trials investigator for Concert Pharmaceuticals, Eli Lilly, and Pfizer; and served on the National Alopecia Areata Foundation—Clinical Research Advisory Council. JK reported being a clinical trial investigator for Concert Pharmaceuticals and receiving consulting fees from Eli Lilly, Concert Pharmaceuticals, and Arena Pharmaceuticals.

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AUTHOR CONTRIBUTIONS

Conceptualization: NM, BK, PM, JK, JC; Funding Acquisition: JC; Investigation: NM, BK, PM, JK, JC; Methodology: NM, BK, PM, JK, JC; Project Administration: JC; Resources: JC; Supervision: NM, JC; Validation: NM, BK, PM, JK, JC; Writing - Review and Editing: NM, BK, PM, JK, JC

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