Original Research

Lichen planopilaris in women: A survey-based study examining baseline hair characteristics and product use in 129 patients seen at Mayo Clinic ☆

Raevti Bole, MD [a], Saranya Wyles, MD, PhD [b,c], Sydney Larkin, BA [c], Reese Imhof, BA [c], Rochelle R. Torgerson, MD, PhD [b,*]

[a] Mayo Clinic Graduate School of Medical Education, Rochester, MN, United States
[b] Mayo Clinic Department of Dermatology, Rochester, MN, United States
[c] Mayo Clinic School of Medicine, Rochester, MN, United States

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ABSTRACT

Background: Cicatricial alopecia is a type of permanent hair loss in which the hair follicle is replaced by scar tissue. Given its relatively low incidence, limited information is available regarding baseline hair characteristics, onset, and other disease-associated factors.
Objective: We sought to further elucidate this information in our lichen planopilaris (LPP) patients.
Methods: Between 1993 and 2016, 505 patients were diagnosed with biopsy-proven LPP. Of these patients, we mailed a 20-question survey to 420 patients with updated mailing address and contact information. Responses were received from 129 of 420 patients for a response rate of 30.7%. A total of 108 patients completed the survey and 21 patients declined participation. Descriptive analysis was performed using JMP software.
Results: Median age at time of pathologic diagnosis was 58 years, with self-reported average age of onset accordingly from 50 to 60 years. Approximately 15% of patients were diagnosed with frontal fibrosing alopecia (FFA), a subtype of LPP. Median follow-up from date of pathologic diagnosis was 72 months. At baseline, 46 out of 108 patients (42.6%) endorsed having thicker hair than peers in childhood. No trend was identified in the rate of traction hairstyle use in childhood, current use of cosmetics, sunscreen, or facial cleanser.
Conclusions: Within our LPP cohort, FFA subtype pathology comprised approximately 15% of cases. There was no trend toward sunscreen use and FFA subtype. Our findings support previously published studies in terms of average age at disease onset, location of hair loss, and median follow-up at 72 months (range: 29–273) from date of pathologic diagnosis.

Introduction

Cicatricial alopecia (CA) is a type of hair loss in which the hair follicle and associated stem cells are destroyed by inflammation and replaced with scar tissue. The prevalence of this disorder is not well studied but, on average, 3 to 7% of patients with hair loss have a cicatricial form (Whiting, 2001). The impact of CA is substantial because hair loss is permanent.

The CA patient population treated at Mayo Clinic Rochester is predominantly lichen planopilaris (LPP) on pathologic analysis.

Studies have found that LPP patients tend to present in their early 50 s with multifocal areas of hair loss and perifollicular erythema or scaling (Mirmirani et al., 2003). A subtype of LPP called frontal fibrosing alopecia (FFA) also exists and is characterized by frontotemporal hairline recession and eyebrow alopecia (Filbrandt et al., 2013).

With regard to the natural history of the disease, LPP is traditionally challenging to diagnose at onset given the significant amount of hair loss that occurs before it is noticed by patient or provider (Gathers et al., 2009). There is often a delay between onset of symptoms and seeking medical care. Given that regrowth of hair is not expected with treatment, the goals of care in these patients are to decrease or halt the progression of hair loss and limit irritative symptoms (Racz et al., 2013). Options for

camouflage of particularly prominent areas should also be explored with the patient.

Given the relatively low incidence, the available information regarding CA is variable and limited in certain areas, such as baseline hair characteristics, etiology, risk factors, and time course. This affects the provider's ability to accurately counsel patients regarding their diagnosis and provide recommendations for treatment. Herein we sought to learn about hair characteristics and perception in LPP patients treated at Mayo Clinic through a questionnaire-based study.

Methods

Between 1993 and 2016, 505 patients with a diagnosis of LPP were evaluated at Mayo Clinic in Rochester, Minnesota. Diagnosis was made by clinical examination at the time of office visit in conjunction with scalp biopsy analysis by fellowship-trained dermatopathologists. Of these patients, 420 were still alive at the time of the study and had updated contact information and mailing addresses. A 20-item questionnaire was developed under the guidance of a faculty dermatologist who underwent subspecialty fellowship training in hair and nails. The question items were authenticated based on validated and nonvalidated surveys, such as the Dermatology Quality of Life Index and questionnaires used in recently published FFA-specific studies exploring the association of skin and hair care products (Aldoori et al., 2016). This survey underwent multiple rounds of revision by faculty reviewers to ensure the clarity of questions.

Our questionnaire addressed the natural history and contributory factors associated with CA (Supplemental File 1). The Mayo Clinic Survey Center was used for survey administration protocol. Given the personal nature of the questions, our survey was sent via mail to give patients adequate time to complete their responses. An additional form was sent with options for patients to call in to complete their survey. Because of our large patient referral base, patients were not required to return for face-to-face visits.

Responses were received from 129 of 420 patients for a response rate of 30.7%. A total of 108 patients completed the questionnaire, and 21 patients declined participation.

Statistical analyses were performed using JMP Version 10 (SAS Institute Inc., Cary, NC). We evaluated the differences in demographic and clinical factors using Wilcoxon-Mann-Whitney test, Pearson's χ^2 test, and Fisher's exact test where indicated. A P value < 0.05 was considered significant. The study was approved by the Mayo Clinic Institutional Review Board.

Results

The final patient cohort consisted of 108 participants. A total of 96 out of 108 (88.9%) were female (Table 1). Median age at patho-

Table 1
Demographic characteristics of the study population.

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Total study population	108
Median age at diagnosis, year	58
Age range	25–84
Median follow-up time, months	72
Range	29–273
Male sex, *n* (%)	12 (11.1)
Diagnosis of FFA, *n* (%)	16 (14.8)
Ancestral origin, *n* (%)	
Caucasian	85 (78.7)
Asian	3 (2.8)
Afro-Caribbean	5 (4.6)
No answer/unknown	15 (13.9)

FFA, frontal fibrosing alopecia.

logic diagnosis was 58 years (range: 25–84). Median follow-up from date of pathologic diagnosis was 72 months (range: 29–273). Sixteen patients (14.8%) were diagnosed with the FFA subtype of LPP (Fig. 1). Self-reported ancestral origin was Caucasian for 85 out of 108 (78.7%), Afro-Caribbean in 5 (4.6%), and Asian in 3 (2.8%). A total of 15 patients (13.8%) did not know their ancestral origin or declined to respond.

With regard to baseline hair characteristics, 68 out of 108 patients (63%) were brunette, 17 blonde (15.7%), 17 black haired (15.7%), and 4 red haired (3.7%; Table 2). Overall, in childhood, 49 out of 108 (45.4%) endorsed having similar hair thickness to their peers, whereas 46 (42.6%) endorsed having thicker hair and 12 (11.1%) endorsed thinner hair. Among the FFA subtype, 9 out of 16 (56.3%) endorsed similar hair thickness, 6 out of 16 (37.5%) endorsed thicker hair, and 1 out of 16 (0.6%) endorsed thinner hair. Of note, 22 out of 108 (20.4%) described having their hair "thinned out" as children, and only one of these had FFA subtype pathology. Overall, childhood eyebrow thickness was endorsed as similar to peers by 54 out of 108 (50.0%), thicker by 39 (36.1%), and thinner by 14 out of 108 responders (13.0%). Among the FFA subtype, 10 out of 16 (62.5%) endorsed thickness similar to peers, whereas 5 out 16 (31.3%) endorsed thicker eyebrows, and 1 out of 16 (6.2%) endorsed thinner eyebrows.

Hair type was described as straight by 50 out of 108 responders (46.3%), wavy by 38 (35.2%), and curly by 19 (17.6%). Hair strands were described as average by 61 out of 108 responders (56.5%), fine by 26 (24.1%), and coarse by 21 (19.4%). When asked for the most common childhood hairstyles, loose or untied hair was most described by 87 out of 155 (56.1%), followed by high ponytails (18/155, 11.6%), two or more braids (18/155, 11.6%), low ponytail (12/155, 7.7%), and hairband (11/155, 7.1%). Average hair length in childhood was above shoulder length.

With regard to current hair characteristics, respondents endorsed a median 50% of their hair remaining compared with childhood. Median frequency of scalp pain or itching was weekly. A total of 44.4% (48/108) used some type of cover up item such as a hairstyle, wig, or hat for their hair loss with no difference identified in the FFA subtype. Average age of onset was in the 50 s to
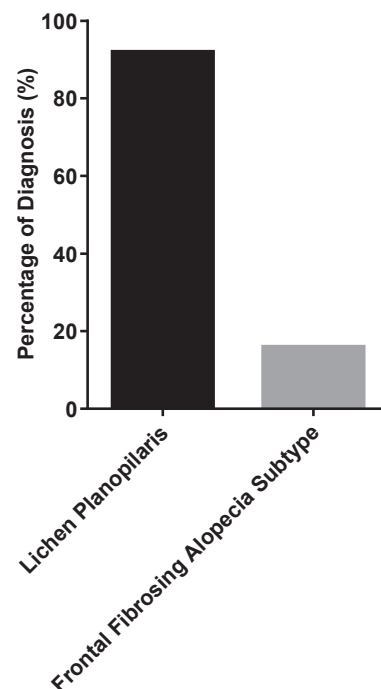
Fig. 1. Proportion of patients with frontal fibrosing alopecia (FFA) subtype.

Table 2
Baseline hair characteristics.

Hair thickness compared to peers, *n* (%)	
Thicker	46 (42.6)
Same	49 (45.4)
Thinner	12 (11.1)
Thinning hair cuts as a child	22 (20.4)
Eyebrow thickness compared to peers, *n* (%)	
Thicker	39 (36.1)
Same	54 (50.0)
Thinner	14 (13.0)
Hair strands, *n* (%)	
Coarse	21 (19.4)
Average	61 (56.5)
Fine	26 (24.1)
Hair type, *n* (%)	
Curly	19 (17.6)
Wavy	38 (35.2)
Straight	50 (46.3)

Table 3
Sunscreen use in LPP patients.

Frequency	*n* (%)
Daily	51 (47.2)
Every other day	9 (8.3)
Weekly	4 (3.7)
Less than weekly	39 (36.1)
Never	5 (4.6)

LPP, lichen planopilaris.

60 s (Fig. 2). A total of 75% of FFA patients presented at 50 to 70 years old, compared with 47.8% of the general LPP subtype (*P* = .015). The most common area of thinning was the top of the head, or vertex scalp, at 49.6% (57/108), followed by frontal thinning at 30.4% (35/108), and back of the head at 11.3% (13/108).

We also sought to elucidate the use of cosmetic and cleansing products in this group of patients (Table 3). The respondents endorsed median sunscreen use every other day, using a dime-sized amount of product. Distribution of sunscreen use frequency was bimodal, with 51 out of 108 patients (47.2%) endorsing daily sunscreen use and 39 out of 108 patients (36.1%) endorsing use less than weekly. There was no significant difference in frequency of sunscreen use in the FFA group (*P* = .31). On average, frequency of facial cosmetics use was every other day, frequency of facial cleanser use was daily, and frequency of hair product use was less than weekly. Distribution of cosmetic and cleanser use frequency was also noted to be bimodal, with 50 out of 108 patients (46.3%) endorsing daily use of cosmetics and 59 out of 108 (54.6%) endorsing daily use of facial cleanser. Conversely, 48 out of 108 patients (44.4%) endorsed less than weekly or no use of cosmetics, and 43 out of 108 patients (39.8%) endorsed less than weekly or no use of facial cleanser.

Approximately 85.4% of the female patients (82/96) endorsed having at least one pregnancy in their lives, at a median age of 24 years old, and 17.1% (14/82) endorsed hair loss with their pregnancy.

Discussion

The majority of LPP respondents in our cohort were Caucasian and female, which is concordant with the literature. Approximately 15% of these patients demonstrated the FFA subtype on pathologic testing. The most common self-reported area of thinning hair was at the top of the head, followed by frontal thinning.

We also evaluated for differences between the overall LPP cohort and the FFA subtype of patients. Whereas LPP typically presents in the early 50 s, FFA has been described in postmenopausal women older than 60 years, in whom diagnosis is often confounded by hair loss caused by normal aging (Dawn et al., 2003; Kossard et al., 1997; Naz et al., 2003). Accordingly, within our cohort, 75% of FFA patients presented at 50 to 70 years old, compared with 47.8% of the general LPP subtype (*P* = .015).

Thicker hair than peers in childhood has been anecdotally described by women with LPP during the history-taking portion of office visits by our providers. To further delineate this correlation, our survey addressed baseline hair characteristics. Overall, the majority of our cohort endorsed having childhood scalp hair density thicker than or similar to their peers. Childhood eyebrow hair density was also described as thicker than or similar to peers by the majority of patients. Recent literature has described *PADI3* as a genetic variant important for hair-shaft type and formation (Malki et al., 2019). This mutation was found predominantly in populations of centrifugal CA in African women, who described thinner, uncombable, and misfolded hair (Malki et al., 2019). Future research determining preservation of this mutation in Caucasian women with LPP or FFA is needed. There was no significant trend toward use of traction hair styles or hair length in childhood.

With regard to symptomology at the time of this survey, frequency of current scalp pain and irritation at a median follow-up of 72 months was weekly or less. This supports the idea that LPP symptoms do undergo some degree of stabilization over time. A total of 44% of patients reported the use of a particular hair style or cover up to minimize their apparent hair loss, which is congruent with the literature (Cevasco et al., 2007). We did not note any clinically significant trends in use of sunscreen, facial cleanser, or cosmetics in either the overall cohort or the FFA subtype. This is a particularly important negative finding because of recent survey-based studies in the literature associating the use of facial cosmetics and sunscreen with the rising incidence of FFA (Aldoori et al., 2016; Debroy et al., 2017). It has been postulated that sebum has a role in contributing to the removal of chemicals from the follicular infundibulum. Because women with FFA tend to be older and have decreased amounts of sebum production, a lead-
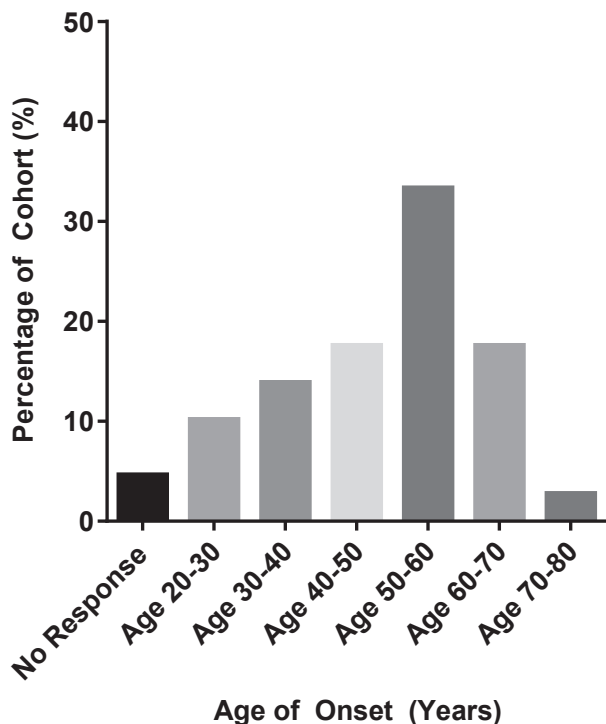
Fig. 2. Age of symptom onset in cohort of lymphocytic cicatricial alopecia patients.

ing theory for sunscreen use and its contribution toward FFA is that low sebum production leads to longer retention of chemicals within the follicular infundibulum (Aldoori et al., 2016; Debroy et al., 2017; Malki et al., 2019). Our research indicates that LPP patients present earlier and are diagnosed at younger ages than FFA patients. This finding may elucidate diverging physiology, with varying degrees of hormonal regulation, between the FFA and LPP subtypes. Future research, perhaps with control groups of age-matched female dermatologists who use sunscreen regularly, is needed to clarify sunscreen use in FFA versus women with FFA or LPP. Furthermore, as the use of sunscreen has multiple implications on population health, additional research is needed to clarify this issue in order to counsel patients effectively.

We acknowledge certain limitations of the study, including lack of a control group and factors associated with survey-based data collection, such as recall bias and patient interpretation of questions. Further analysis of the data could include investigation of discrepancies between responders and nonresponders because this may elucidate additional differences in the LPP/FFA cohorts. One strength of this study is that, as a tertiary referral center, the Mayo Clinic patient population surveyed is not limited by geographic region.

Conclusions

The purpose of this study was to further elucidate the baseline hair characteristics, time course, and comorbid factors associated with LPP and FFA. Baseline scalp and facial hair characteristics of this cohort indicate that the majority of LPP patients report thicker hair density or similar hair density compared with peers. We found that FFA subtype pathology comprised approximately 15% of our LPP population. Contrary to recent literature, we did not find a trend toward use of sunscreen and facial cosmetics in either the LPP or FFA subtype of CA patients. Our findings do support previously published studies in terms of disease onset and location of hair loss and additionally provide a long-term median follow-up of 72 months from the date of pathologic diagnosis.

Conflict of Interest

None

Funding

Study Approval

The authors confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijwd.2019.10.004.

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