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# Incidence estimates for lichen planopilaris and frontal fibrosing alopecia in a New York City health care system

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## Abstract

Lichen planopilaris (LPP) and frontal fibrosing alopecia (FFA) are scarring alopecias that cause significant distress and psychological morbidity. Limited studies have been performed examining the epidemiology of FFA and LPP. We performed a retrospective case cohort analysis by querying for patients with the ICD 10 code L66.1 (LPP, FFA) between 2015 and 2018 using the Clinical Data Warehouse (CDW) at NewYork-Presbyterian Hospital and Columbia Doctors. We calculated the one-year incidence of LPP/FFA between January 1, 2018 to December 31, 2018 by identifying all patients without a previously recorded ICD code for L66.1 who presented as a new hair loss patient based on chart review. A total of 170 patients were identified with a new diagnosis of LPP or FFA in 2018 among 1,187,583 patients. The standardized incidence per 100,000 was 12.75 for LPP and FFA combined, 7.35 for LPP alone, and 5.41 for FFA alone. The incidence peaked in the 51 to 60 age range (3.36). The incidence was highest in non-Hispanic White patients (17.27), White patients of unknown ethnicity (26.26), and non-Hispanic Asian patients (17.27). In New York City, LPP and FFA are uncommon diseases that are most common in middle-aged females and non-Hispanic White patients.

*Keywords: epidemiology, frontal fibrosing alopecia, incidence, lichen planopilaris*

## Introduction

Lichen planopilaris (LPP) and frontal fibrosing alopecia (FFA) are primary cicatricial alopecias characterized by an inflammatory lymphocytic infiltrate. The literature on its epidemiology remains limited and the majority of published studies are marked by small sample sizes [1,2]. We previously reported the prevalence estimates of LPP and FFA, as well as their associated comorbidities [3,4]. However, the true overall incidence of LPP and FFA is unknown. To address this, we performed a retrospective cohort study at Columbia University Irving Medical Center (CUIMC).

## Methods

We performed a retrospective case cohort analysis by querying for patients with the ICD 10 code L66.1 (LPP, FFA) between 2015 and 2018 using the Clinical Data Warehouse (CDW). The CDW captures data from NewYork-Presbyterian Hospital (NYP) and Columbia Doctors, both of which are affiliated with CUIMC.

The one-year incidence of LPP/FFA between January 1, 2018 to December 31, 2018 was calculated by identifying all patients without a previously recorded ICD code for L66.1 who presented as a new hair loss patient based on chart review. Anyone in our health system who had an ICD code for LPP/FFA before

2018 was excluded and anyone who had a subjective history of hair loss before 2018 was excluded. Patients who were transferring care to CUIMC for previously diagnosed hair loss were excluded from our cohort based on chart review if they provided any subjective history of receiving treatment for any type of alopecia in the past. We calculated the incidence by dividing this cohort by all patients in the health system who did not previously have a diagnosis of L66.1 during the same time frame.

Through chart review, we previously validated that all confirmed cases included in our analysis had findings consistent with LPP/FAA based on clinical and/or histologic criteria [3,4].

We analyzed the demographic characteristics of the LPP/FAA cohort identified January 1, 2018 through December 31, 2018. Lichen planopilaris and FAA were analyzed individually and together in a combined group. Sex- and age-specific LPP and FAA incidence values were calculated for the following 5

**Table 1.** Demographic information for patients with lichen planopilaris and frontal fibrosing alopecia who were diagnosed in the NewYork-Presbyterian and Columbia Doctors health systems in 2018.

Category	Overall (N=170)	LPP (N=94)	FAA (N=76)	No FFA/LPP (N=1,187,583)
Sex	N (%)	N (%)	N (%)	N (%)
Female	131 (77.1)	67 (71.3)	64 (84.2)	675,563 (56.9)
Male	38 (22.4)	27 (28.7)	11 (14.5)	512,020 (43.1)
<b>Age</b>				
1 to 10	0 (0.0)	0 (0.0)	0 (0.0)	124,472 (10.5)
11 to 20	0 (0.0)	0 (0.0)	0 (0.0)	114,711 (9.7)
21 to 30	7 (4.1)	6 (6.4)	1 (1.3)	153,069 (12.9)
31 to 40	37 (21.8)	28 (29.8)	9 (11.8)	172,628 (14.5)
41 to 50	32 (18.8)	17 (18.1)	15 (19.7)	140,854 (11.9)
51 to 60	37 (21.8)	20 (21.3)	17 (22.4)	147,913 (12.4)
61 to 70	34 (20.0)	10 (10.6)	24 (31.6)	144,673 (12.2)
71 to 80	20 (11.8)	10 (10.6)	10 (13.2)	113,106 (9.5)
81 to 90	3 (1.8)	3 (3.2)	0 (0.0)	58,556 (4.9)
91 +	0 (0.0)	0 (0.0)	0 (0.0)	19,147 (1.6)
<b>Race x ethnicity</b>				
<b>White</b>				
Hispanic	6 (8.6)	3 (7.9)	3 (9.4)	97,393 (24.9)
Non-Hispanic	43 (61.4)	24 (63.2)	19 (59.4)	213,359 (54.5)
Unknown	21 (30.0)	11 (29.0)	10 (31.3)	80,805 (20.6)
<b>Black or African American</b>				
Hispanic	0 (0.0)	0 (0.0)	0 (0.0)	18,843 (22.6)
Non-Hispanic	1 (50.0)	0 (0.0)	1 (100.0)	39,330 (47.1)
Unknown	1 (50.0)	1 (100.0)	0 (0.0)	25,32 (30.3)
<b>Asian</b>				
Hispanic	0 (0.0)	0 (0.0)	0 (0.0)	3,568 (12.0)
Non-Hispanic	5 (83.3)	1 (50.0)	4 (100.0)	17,292 (58.2)
Unknown	1 (16.7)	1 (50.0)	0 (0.0)	8,852 (29.8)
<b>Other</b>				
Hispanic	0 (0.0)	0 (0.0)	0 (0.0)	20,650 (46.3)
Non-Hispanic	0 (0.0)	0 (0.0)	0 (0.0)	6,546 (14.7)
Unknown	0 (0.0)	0 (0.0)	0 (0.0)	17,408 (39.0)
<b>Unknown</b>				
Hispanic	5 (5.4)	3 (5.7)	2 (5.1)	70,925 (11.1)
Non-Hispanic	2 (2.2)	1 (1.9)	1 (2.6)	24,414 (3.8)
Unknown	85 (92.4)	49 (92.5)	36 (92.3)	544,422 (85.1)

Other includes "Other, American Indian/Alaskan Native, Native Hawaiian/Other Pacific Islands."

groups: White, Black, Asian, unknown, and other (including American Indian, Alaskan Native, and Native Hawaiian/Pacific Islander). Each racial group was further examined by ethnicity (Hispanic, non-Hispanic, or unknown) as was self-identified by patients in the medical record. The entire living population for each group was considered at-risk. To calculate sex- and age-specific LPP and FFA incidence estimates for the overall population, the number of LPP and FFA cases and the total cohort size (including both cases and controls) were used. We applied direct standardization to allow for subgroup comparisons using the projected U.S. population in 2000 as the standard population and the following 10 age groups: 1 to 10, 11 to 20, 21 to 30, 31 to 40, 41 to 50, 51 to 60, 61 to 70, 71 to 80, 81 to 90, and above 91 years. Estimates were age- and sex-adjusted for age group comparisons, and sex- and age-adjusted for race and ethnicity comparisons. Crude and standardized incidence estimates were calculated based on patients with available race, sex, and age information. All analyses were performed using Statistical Analysis System (SAS), Version 9.4.

## Results

Query of the electronic health records identified that 173 patients had a new ICD code of L66.1 in the calendar year 2018. There were a total of 1,189,507 patients in the health system without an ICD code of L66.1 Three patients had transferred care from other health systems seeking second opinions and therefore were excluded from the cohort, leaving 170 patients (94 LPP; 76 FFA).

Demographic information for the patient (LPP or FFA) and control (no LPP or FFA) cohorts are reported in **Table 1**. The majority of LPP and FFA patients were female (77.1%). The most commonly represented race/ethnicity was White non-Hispanic (25.2% of patients). We previously reported comorbidities for these groups [3]. The standardized incidence per 100,000 was 12.75 for LPP and FFA combined, 7.35 for LPP alone, and 5.41 for FFA alone (**Table 2**). We observed a higher incidence in females compared to males both in the combined group and for LPP and

FFA alone (17.3 versus 8.00 for combined; 9.9 versus 5.3 for LPP; 9.5 versus 2.5 for FFA). The incidence was highest in patients between ages 30 to 80 years and peaked in the 51 to 60 age range (incidence for combined group: 3.36, LPP: 1.81, FFA: 1.54). We observed the highest incidence in non-Hispanic White patients (17.27), White patients of unknown ethnicity (26.26), and non-Hispanic Asian patients (19.43), **Table 2**. This held true for LPP alone (10.4 for Non-Hispanic White patients; 16.30 for White patients of unknown ethnicity). For FFA alone, standardized incidence was highest for Asian Non-Hispanic patients (15.88) followed by White patients of unknown ethnicity (9.96) and White Non-Hispanic patients (6.87).

## Discussion

In this study, we have determined the overall and group-specific adjusted incidence estimates for LPP and FFA in a large cohort study at NewYork-Presbyterian hospital. We had a total of 1,189,507 patients in our study and 170 patients had a new diagnosis of LPP or FFA in the year 2018. The overall standardized incidence of LPP and FFA combined was 12.75 and there was a higher incidence in females compared to males (17.3 in females versus 8.00 in males). The incidence was highest in the 51 to 60 age range and the majority of our patients were over the age of 50 years old (55%). No patients in our study were younger than 20 years of age. When examining race and ethnicity, the diseases had highest incidence in non-Hispanic White and Asian patients. They were less common in Black patients in similarity with our previously published prevalence findings and the existing literature [2,4,5]. Other studies have reported incidence of LPP at large hair research centers with annual rates ranging between 1.15% to 7.59% [1]. They have similarly found that LPP and FFA are most common in women aged 50 to 60 years.[6].

To the best of our knowledge, this is the first study to examine incidence of LPP and FFA among a large population including control subjects. Limitations of our study include the retrospective analysis, incompleteness of medical records, and lack of gold

standard diagnostic criteria for LPP/FFA. Additionally, this is a single center study performed in New York City so results may not be generalizable to the entire U.S. population.

## Conclusion

This is a large study examining LPP and FFA incidence across race, ethnicity, and gender. Both LPP and FFA are rare conditions with similar incidence. They are more common in female patients and seem to be predominant in the middle-age range (post-menopausal women over 50 years old).

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## Potential conflicts of interest

The authors declare no conflicts of interest.

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**Table 2.** Overall and age-adjusted sex and race incidence values in 2018. Incidence values are indicated as cases per 100,000.

Characteristic	No. of LPP/FFA Cases	Crude Incidence	Standardized Incidence	No. of LPP Cases	Crude Incidence	Standardized Incidence	No. of FFA Cases	Crude Incidence	Standardized Incidence
All	170	14.3	12.75	94	7.9	7.35	76	6.4	5.41
<b>Age adjusted sex incidence and age distributions</b>									
Female	131(77.1)	19.4	17.36	67 (71.3)	9.9	8.90	64 (84.2)	9.5	8.45
Male	38 (22.4)	7.4	8.00	27 (28.7)	5.3	5.74	11 (14.5)	2.5	2.25
Age									
1 to 10	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
11 to 20	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
21 to 30	7 (4.1)	4.6	0.64	6 (6.4)	3.9	0.55	1 (1.3)	0.7	0.09
31 to 40	37 (21.8)	21.4	2.83	28 (29.8)	16.2	2.14	9 (11.8)	5.2	0.69
41 to 50	32 (18.8)	22.7	3.27	17 (18.1)	12.1	1.74	15 (19.7)	10.6	1.53
51 to 60	37 (21.8)	25.0	3.36	20 (21.3)	13.5	1.81	17 (22.4)	11.5	1.54
61 to 70	34 (20.0)	23.5	2.13	10 (10.6)	6.9	0.63	24 (31.6)	16.6	1.51
71 to 80	20 (11.8)	17.7	0.92	10 (10.6)	8.8	0.46	10 (13.2)	8.8	0.46
81 to 90	3 (1.8)	5.1	0.14	3 (3.2)	5.1	0.14	0 (0.0)	0	0
91 +	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
<b>Age-adjusted race prevalence</b>									
<b>White</b>									
Hispanic	6 (8.6)	6.1	6.89	3 (7.9)	3.1	4.17	3 (9.4)	3.1	2.72
Non-Hispanic	43 (61.4)	20.2	17.27	24 (63.2)	11.2	10.4	19 (59.4)	8.9	6.87
Unknown	21 (30.0)	26.0	26.26	11 (29.0)	13.6	16.30	10 (31.3)	12.4	9.96
<b>Black or African American</b>									
Hispanic	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
Non-Hispanic	1 (50.0)	2.5	2.33	0 (0.0)	0	0	1 (100.0)	2.5	2.33
Unknown	1 (50.0)	3.9	3.46	1 (100.0)	3.9	3.45	0 (0.0)	0	0
<b>Asian</b>									
Hispanic	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
Non-Hispanic	5 (83.3)	28.9	19.43	1 (50.0)	5.8	3.55	4 (100.0)	23.1	15.88
Unknown	1 (16.7)	11.3	5.38	1 (50.0)	11.3	5.38	0 (0.0)	0	0
<b>Other</b>									
Hispanic	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
Non-Hispanic	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0
Unknown	0 (0.0)	0	0	0 (0.0)	0	0	0 (0.0)	0	0

<b>Unknown</b>									
Hispanic	5 (5.4)	7.0	8.16	3 (5.7)	4.2	5.20	2 (5.1)	2.8	2.32
Non-Hispanic	2 (2.2)	8.2	4.89	1 (1.9)	4.1	4.89	1 (2.6)	4.1	0
Unknown	85 (92.4)	15.6	13.32	49 (92.5)	9.0	7.65	36 (92.3)	6.6	5.68

*FFA, frontal fibrosing alopecia; LPP, lichen planopilaris.*