The psychologic impact of loose anagen syndrome and short anagen syndrome

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Abstract

Loose anagen syndrome (LAS) and short anagen syndrome (SAS) are congenital hair disorders presenting with reduced hair length with or without hair thinning. We conducted a non-validated online questionnaire of self-identified familial participants in a Facebook support group to assess psychologic symptoms, including anxiety, depression, low self-esteem, sadness, insecurity, worry, frustration, and body dysmorphia, in patients and their caregivers. Of 163 total respondents, negative psychologic symptoms were reported in 44.2% (38/89) of LAS patients, 48.3% (43/89) of LAS caregivers, 56.8% (42/74) of SAS patients, and 47.2% (35/74) of SAS caregivers. Our data indicate that both LAS and SAS have strong psychologic, emotional, and social impacts on affected children and their caregivers.

KEYWORDS

bullying, hair disease, hair disorders, loose anagen syndrome, mental health, psychology, quality of life, registry, short anagen syndrome

BRIEF REPORT 1

Loose anagen syndrome (LAS) and short anagen syndrome (SAS) are rare congenital hair disorders that present with reduced hair length with or without hair thinning. LAS is caused by irregular keratinization of the inner root sheath leading to abnormal anchoring of the hair shaft and, subsequently, premature loss of anagen hairs.¹ In addition to short hair that barely reaches the shoulder, patients may have low hair density and unruly or knotted hair. SAS is characterized by an inability to grow long hair due to shortened anagen. These patients usually have short hair and complain of recurrent hair shedding.² Both LAS and SAS have been mostly reported in young Caucasian girls with light-colored hair, though cases have also been described in different ethnicities and in adults.^{3,4}

Pediatric hair loss disorders have been associated with bullying, decreased self-esteem, and reduced quality of life.⁵ To date, no studies have examined these consequences in patients with LAS/SAS and their families. We conducted a non-validated guestionnaire of our design, developed in conjunction with a psychologist, and distributed to 2259 active members of an online LAS/SAS support group. Members self-reported having been diagnosed by a dermatologist with LAS/SAS. This study was approved by the University of Miami Institutional Review Board.

A total of 163 patients or their caregivers completed the guestionnaire (7.2% response rate): 89 with LAS (mean age of symptom onset (SD) = 2.3 (0.86) years; mean age at diagnosis (SD) = 5.3 (4.87)years; mean age at time of questionnaire (SD) = 8.5 (7.78) years; 99% female; 95.5% White; 6.7% Latino or Hispanic; 2.2% Asian) (Table 1) and 74 with SAS (mean age of symptom onset (SD) = 2.5 (4.62) years; mean age at diagnosis (SD) = 5.1 (4.95) years; mean age at time of questionnaire (SD) = 9.1 (8.22) years; 99% female; 98% White; 5% Latino or Hispanic; 1% Asian) (Table 2).

Negative psychologic symptoms were reported in 42.7% (38/89) of respondents with LAS (Table 1). The most common symptoms

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TABLE 1 Demographics, psychologic symptoms, and psychiatric treatments of survey respondents with LAS and the psychologic symptoms of their caregivers

Tatal Number of Dauticinents with 1 AC2	N = 89
Total Number of Participants with LAS ^a	
Mean age of symptom onset, years (SD)	2.3 (0.86)
Mean age at diagnosis, years (SD)	5.3 (4.87)
Mean age at time of questionnaire, years (SD)	8.5 (7.78)
Female	88 (98.9%)
White	85 (95.5%)
Hispanic or Latino	6 (6.7%)
Asian	2 (2.2%)
Number of individuals reporting bullying or mistreatment from peers	30 (33.7%)
Number of individuals with negative psychologic symptoms	38 (42.7%)
Anxiety	20
Depression	11
Other- low self-esteem, sadness, insecure, worry, frustration, body dysmorphia	21
Number of individuals receiving treatment	1 (2.6%)
Professional therapy	1
Number of caregivers with negative psychologic symptoms	43 (48.3%)
Anxiety	33
Depression	18
Other- worry, sadness, frustration, stress	15
Number of caregivers receiving treatment	7 (16.3%)
Professional therapy	3
Fluoxetine	2
Sertraline	1
Other- CBD	1

^aParticipants could identify with one or more ethnicities.

reported were anxiety (52.6%, 20/38), depression (28.9%, 11/38), and "Other" symptoms that included low self-esteem, sadness, insecurity, worry, frustration, and body dysmorphia (31.6%, 12/38). Among this group, only one respondent received formal treatment (e.g., psychotherapy). Approximately one-third (33.7%, 30/89) of children with LAS reported bullying or mistreatment from peers. Of interest, caregivers more frequently reported negative psychologic symptoms compared to their children (48.3%, 43/89). Among this group, anxiety (76.7%, 33/43) and depression (18.6%, 8/43) were most common. More caregivers reported receiving treatment (16.3%, 7/43) compared to their children.

Compared to respondents with LAS, a higher percentage of respondents with SAS (56.8%, 42/74) reported negative psychologic symptoms (Table 2). The most common symptoms reported were "Other" symptoms that included low self-esteem, sadness, insecurity, worry, frustration, and body dysmorphia (59.5%, 25/42), followed by anxiety (35.7%, 15/42) and depression (26.2%, 11/42). Although more than half of SAS respondents reported negative psychologic

TABLE 2Demographics, psychologic symptoms, and psychiatrictreatments of survey respondents with SAS and the psychologicsymptoms of their caregivers

Total Participants with SAS ^a	N = 74
Mean age of symptom onset, years (SD)	2.3 (4.62)
Mean age at diagnosis, years (SD)	5.3 (4.95)
Mean age at time of questionnaire, years (SD)	9.1 (8.22)
Female	73 (98.6%)
White	72 (97.3%)
Hispanic or Latino	6 (8.1%)
Asian	1 (1.3%)
Number of individuals reporting bullying or mistreatment from peers	28 (37.8%)
Number of individuals with negative psychologic symptoms	42 (56.8%)
Anxiety	15
Depression	11
Other- sadness, low self-esteem, insecure, worry, body dysmorphia	25
Number of individuals receiving treatment for psychologic symptoms	4 (9.5%)
Fluoxetine + professional therapy	2
Professional therapy only	2
Number of caregivers with negative psychologic symptoms	35 (47.3%)
Anxiety	27
Depression	7
Other- worry, sadness, frustration, stress	9
Number of caregivers receiving treatment	3 (8.6%)
Professional therapy	2
Escitalopram	1

^aParticipants could identify with one or more ethnicities.

symptoms, only 9.5% (4/42) reported receiving treatment. Over onethird of participants (37.8%, 28/74) reported bullying or mistreatment by peers. Caregivers also reported experiencing negative psychologic symptoms (47.2%, 35/74) due to their children's diagnosis. Anxiety was the most common symptom reported (77.1%, 27/35), followed by depression (20.0%, 7/35) and "Other" symptoms that included worry, sadness, and frustration (25.7%, 9/35). Only 8.6% of caregivers (3/35) reported receiving treatment for their symptoms.

This study has several limitations, including sampling bias, low response rate, and response bias. Our data may overestimate negative psychologic symptoms in parents of LAS/SAS patients, as these individuals may be more likely to join an online support group. Because the diagnosis is self-reported, we do not know with certainty that patients were truly diagnosed with LAS/SAS, meriting further study prospectively in physician-diagnosed patients. There could also be variations in survey participants' definitions of certain negative psychologic symptoms (e.g., depression, anxiety, etc.) because questions were not validated and standardized. Our data indicate that LAS and SAS have strong psychologic, emotional, and social impacts on affected children and their caregivers. Pediatric alopecia areata has similarly been associated with negative psychologic/emotional symptoms in 48% of children and bullying in 23% of children.⁵ Reported rates of psychologic therapy are low for LAS and SAS respondents. These findings indicate the need for providers to be aware of the impact that hair loss can have on patients' quality of life and to provide sufficient mental health resources for patients and their caregivers. Future studies with standardized assessments will allow for accurate comparison to other conditions and a better understanding of the overall quality of life impact associated with LAS and SAS.

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CONFLICT OF INTEREST

Michael Randolph, Eran Gwillim, and Betty Nguyen have nothing to disclose. Antonella Tosti is a consultant for DS Laboratories, Monat Global, Almirall, Thirty Madison, Eli Lilly, Bristol Myers Squibb, P&G, Pfizer, and Myovant, and Principal Investigator for Eli Lilly, Pfizer, and Erchonia.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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