Title: The Invisible Impact of a Visible Disease: Psychosocial Impact of Alopecia Areata

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Short title: Psychosocial impact of alopecia areata

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Figure S1

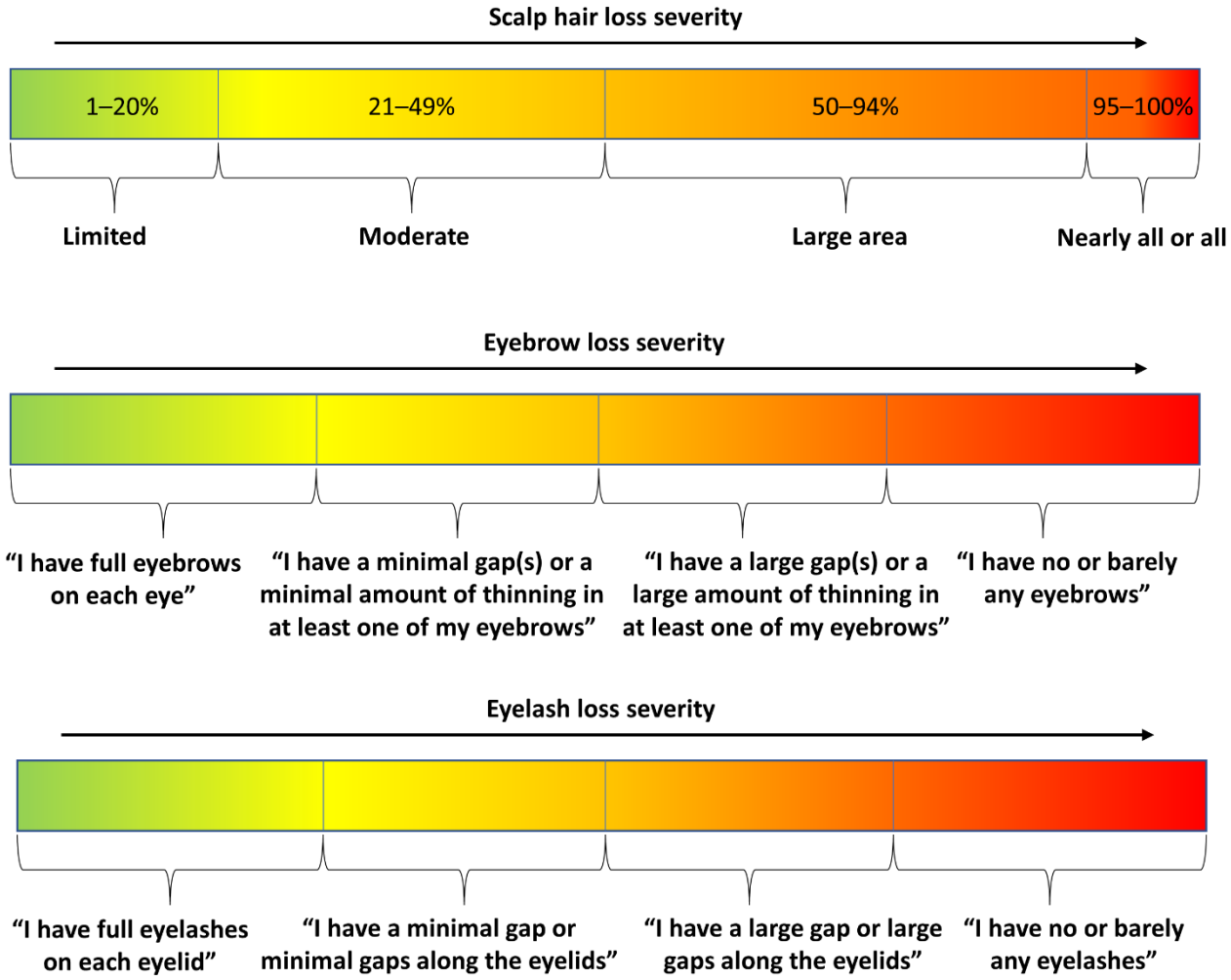
Scalp hair loss severity
1–20%
21–49%
50–94%
95–100%
Limited
Moderate
Large area
Nearly all or all
Eyebrow loss severity
"I have full eyebrows on each eye"
"I have a minimal gap(s) or a minimal amount of thinning in at least one of my eyebrows"
"I have a large gap(s) or a large amount of thinning in at least one of my eyebrows"
"I have no or barely any eyebrows"
Eyelash loss severity
"I have full eyelashes on each eyelid"
"I have a minimal gap or minimal gaps along the eyelids"
"I have a large gap or large gaps along the eyelids"
"I have no or barely any eyelashes"

Table S2. Demographics and clinical characteristics by scalp hair loss severity

Parameter	**Scalp hair loss severity (mean [SE]/ n [%])**				***P* value**
	Limited area (n = 99)	**Moderate area (n = 92)**	**Large area (n = 100)**	**Nearly all or all (n = 253)**	
Age, years	43.5 (1.5)	42.0 (1.5)	45.0 (1.5)	46.0 (0.9)	0.126
Gender					0.034
Female	75 (75.8%)	78 (84.8%)	82 (82.0%)	181 (71.5%)	
Male	24 (24.2%)	14 (15.2%)	18 (18.0%)	72 (28.5%)	
Race					0.002
American Indian or Alaska Native	0 (0.0%)	1 (1.1%)	0 (0.0%)	2 (0.8%)	
Asian	10 (10.1%)	5 (5.4%)	1 (1.0%)	6 (2.4%)	
Black or African American	17 (17.2%)	18 (19.6%)	23 (23.0%)	28 (11.1%)	
Native Hawaiian or Other Pacific Islander	0 (0.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	
White	60 (60.6%)	57 (62.0%)	64 (64.0%)	194 (76.7%)	
Multi-racial	9 (9.1%)	7 (7.6%)	5 (5.0%)	12 (4.7%)	
Other	3 (3.0%)	1 (1.1%)	5 (5.0%)	10 (4.0%)	
Prefer not to answer	0 (0.0%)	3 (3.3%)	1 (1.0%)	1 (0.4%)	
Relationship Status					0.268

Single	31 (31.3%)	32 (34.8%)	37 (37.0%)	69 (27.3%)	
Married	46 (46.5%)	34 (37.0%)	34 (34.0%)	129 (51.0%)	
Domestic partnership, unmarried	10 (10.1%)	13 (14.1%)	15 (15.0%)	19 (7.5%)	
Separated or divorced	9 (9.1%)	10 (10.9%)	9 (9.0%)	27 (10.7%)	
Widowed	1 (1.0%)	1 (1.1%)	4 (4.0%)	6 (2.4%)	
Prefer not to answer	2 (2.0%)	2 (2.2%)	1 (1.0%)	3 (1.2%)	
Employment Status					0.616
Full-time work	56 (56.6%)	57 (63.3%)	59 (59.0%)	151 (60.4%)	
Part-time work	12 (12.1%)	11 (12.2%)	15 (15.0%)	25 (10.0%)	
Homemaker/housewife	6 (6.1%)	3 (3.3%)	2 (2.0%)	9 (3.6%)	
Student	4 (4.0%)	1 (1.1%)	5 (5.0%)	15 (6.0%)	
Unemployed	10 (10.1%)	7 (7.8%)	5 (5.0%)	12 (4.8%)	
Retired	7 (7.1%)	7 (7.8%)	8 (8.0%)	30 (12.0%)	
Disabled	4 (4.0%)	4 (4.4%)	6 (6.0%)	8 (3.2%)	
Duration of experiencing AA symptoms	11.8 (1.4)	10.7 (1.4)	18.8 (1.4)	22.7 (0.9)	<0.001
Duration of AA diagnosis by provider	10.6 (1.3)	9.6 (1.4)	15.1 (1.3)	21.5 (0.8)	<0.001
Current episode of hair loss lasted for					<0.001
Less than 6 months	14 (14.1%)	5 (5.4%)	2 (2.0%)	3 (1.2%)	
6 months – 1 year	23 (23.2%)	12 (13.0%)	4 (4.0%)	4 (1.6%)	

1–2 years	14 (14.1%)	11 (12.0%)	7 (7.0%)	11 (4.3%)	
2–4 years	14 (14.1%)	16 (17.4%)	8 (8.0%)	27 (10.7%)	
Greater than 4 years	34 (34.3%)	48 (52.2%)	79 (79.0%)	208 (82.2%)	
Current pattern of hair loss					<0.001
AA monolocularis (single spot)	16 (16.2%)	3 (3.3%)	0 (0.0%)	0 (0.0%)	
AA multilocularis/patchy (multiple spots)	67 (67.7%)	64 (69.6%)	32 (32.0%)	2 (0.8%)	
Ophiasis (wave-shaped hair loss at the circumference of the head)	9 (9.1%)	14 (15.2%)	13 (13.0%)	0 (0.0%)	
AA totalis (complete or near complete hair loss on the scalp)	3 (3.0%)	4 (4.3%)	36 (36.0%)	47 (18.6%)	
AA universalis (complete or near complete loss of all body hair)	4 (4.0%)	7 (7.6%)	19 (19.0%)	204 (80.6%)	
Eyebrow: Current					<0.001
I have full eyebrows on each eye	45 (45.5%)	35 (38.0%)	25 (25.0%)	9 (3.6%)	
I have a minimal gap(s) or a minimal amount of thinning in at least one of my eyebrows	29 (29.3%)	21 (22.8%)	24 (24.0%)	12 (4.7%)	
I have a large gap(s) or a large amount of thinning in at least one of my eyebrows	12 (12.1%)	17 (18.5%)	22 (22.0%)	23 (9.1%)	
I have no or barely any eyebrows	13 (13.1%)	19 (20.7%)	29 (29.0%)	209 (82.6%)	

Upper and Lower Eyelashes: Current					<0.001
I have full eyelashes on each eyelid	58 (58.6%)	42 (45.7%)	38 (38.0%)	27 (10.7%)	
I have a minimal gap or minimal gaps along the eyelids	26 (26.3%)	27 (29.3%)	23 (23.0%)	20 (7.9%)	
I have a large gap or large gaps along the eyelid	9 (9.1%)	9 (9.8%)	14 (14.0%)	29 (11.5%)	
I have no or barely any eyelash	6 (6.1%)	14 (15.2%)	25 (25.0%)	177 (70.0%)	

Abbreviations: AA – Alopecia Areata, SE – Standard Error

Table S3. Item-wise scores on the Alopecia Areata Quality of Life Index Questionnaire

Item	Patients (n=547), mean (SD)
Subjective symptoms	
I worry about having this hair problem for the rest of my life	3.4 (1.0)
I cannot forget that I have this hair problem	3.4 (0.9)
I am sad about the appearance of my hair/eyebrows/eyelashes	3.3 (1.0)
I feel uncomfortable using a wig	2.8 (1.2)
I tend to hide my scalp with hats or bandanas	2.8 (1.2)
I worry that it might spread	2.6 (1.3)
It costs me a lot of money to look after my hair	2.6 (1.3)
I am afraid my children may have alopecia areata	2.6 (1.3)
I do not take my wig/hat/bandana off in front of my partner	2.2 (1.2)
Relationships	
I think that other people notice my hair/eyebrows/eyelashes problem	3.2 (1.0)
I have to explain to others what is wrong with my hair/eyebrows/eyelashes	2.9 (1.1)

I am embarrassed when going out to a party	2.6 (1.1)
I feel that people find it unpleasant to look at me	2.5 (1.1)
I am afraid that other people think my hair looks badly cared for	2.5 (1.2)
I feel I have sexual difficulties because of alopecia areata	2.2 (1.2)
I feel I have difficulties in establishing relationships with friends and/or relatives	2.1 (1.2)
My work/studying has deteriorated because of alopecia areata	1.9 (1.1)
I feel that others are afraid of catching diseases from me	1.6 (1.0)
Objective signs	
My scalp is visible	3.5 (0.9)
I feel itchy on my scalp	2.5 (1.2)
I lose tufts of hair when I comb or shampoo	2.3 (1.3)

Abbreviations: SD – Standard Deviation