
Severity of disease and quality of life in parents of children with alopecia areata, totalis, and universalis: A prospective, cross-sectional study



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Background: Caregiver-oriented quality of life (QoL) research in alopecia areata is limited. No study has used a parent-tailored survey to examine the relationship between QoL and severity of alopecia as measured by Severity of Alopecia Tool (SALT) scores.

Objectives: This is a prospective study that describes QoL in parents of pediatric patients with all subtypes of alopecia areata and investigates the relationship between QoL and severity of disease, duration of disease, and age of patients.

Methods: Pediatric patients and their parents were invited to participate during clinic visits. Participating parents completed the Quality of Life in a Child's Chronic Disease Questionnaire (QLCCDQ) and the Family Dermatology Life Quality Index (FDLQI). A subset of children completed the Children's Dermatologic Life Quality Index (CDLQI). SALT scores at time of survey completion were recorded.

Results: In total, 153 patients were included. Significant mild-to-moderate negative correlations were found between SALT scores and FDLQI scores, QLCCDQ scores, and QLCCDQ emotional domain scores. Age of child correlated negatively with QLCCDQ scores but not FDLQI scores. No significant correlation was found between duration of disease and FDLQI scores, QLCCDQ scores, or QLCCDQ emotional domain scores.

Limitations: This study is limited by its small sample size and cross-sectional design.

Conclusions: Impaired parent QoL might be associated with increasing severity of disease and age of affected child but not duration of disease. Providers should tailor counseling accordingly and help parents set realistic expectations for long-term experience with the disease. (J Am Acad Dermatol 2019;80:1389-94.)

Key words: alopecia areata; alopecia totalis; alopecia universalis; hair loss; Severity of Alopecia Tool; quality of life.

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Alopecia areata (AA), alopecia totalis (AT), and alopecia universalis (AU) are variants of autoimmune, nonscarring alopecia that most frequently affects the scalp but might also affect the eyebrows and eyelashes (AT) and body hair (AU).¹ Due to their visibility, lack of curative therapy, and chronic nature, AA and its variants can create a significant psychosocial burden for patients.² Studies have shown higher rates of anxiety and depression, as well as a negative impact on self-confidence, self-esteem, body satisfaction, and sense of self-worth among AA patients.³ Variability in outcomes, unpredictability of disease course, and lack of curative therapies contribute to the frustration that patients and their caregivers often experience.

Although many studies have been conducted to determine psychosocial impact from the patient perspective, caregiver-oriented research is limited.^{2,4} A recent study by Liu et al used a family-centered questionnaire and found that parents of children with AA reported significant emotional distress and greater impairment in quality of life (QoL) than their children.⁵ This study did not, however, find a correlation between severity of disease and parents' QoL. Moreover, no study has used a parent-tailored survey to examine the relationship between QoL and severity of alopecia as measured by Severity of Alopecia Tool (SALT) scores. A better examination of this relationship could help guide disease management and enable clinicians to tailor support for patients and their parents.

QoL investigations have been conducted in parents of children affected with atopic dermatitis and psoriasis.^{6,7} Results from these studies have shown that pediatric chronic dermatoses affect the emotional well-being, burden of care, and day-to-day life of parents.^{8,9} These factors are significant in their implication on treatment options, adherence to management, and long-term positive outcomes for the children affected.^{8,9} A similar study in parents of children with AA could thus be used to guide management, identify obstacles to care, and provide supportive strategies for patients and parents.

This is a multicenter, prospective study conducted through the Pediatric Dermatology Research Alliance to describe and evaluate QoL in parents of pediatric patients with all subtypes of alopecia areata (AA, AT, and AU). Secondary objectives were to

investigate the relationship between QoL and severity of disease, duration of disease, and age of patients. We predicted that parents of children with AA would report impaired QoL and emotional distress. We also predicted that greater impact on parent QoL would correlate with shorter time since child's diagnosis, increased disease severity, and increasing age of child.

CAPSULE SUMMARY

- Chronic disease affects parent's quality of life.
- Awareness of the impact of alopecia areata on the emotional health of parents should lead to more family-centered care for this disease. Parents need support systems as much as children do.

MATERIALS AND METHODS

Participants

During April 2017-July 2018, parent and patient participants were recruited from the Children's Hospital of Philadelphia, University of California Los Angeles Medical Center, and Nationwide Children's Hospital. English-speaking

parents or legal guardians of pediatric patients with AA, AT, or AU diagnosed for at least 1 month were invited to participate. The diagnosis was confirmed by a pediatric dermatologist, and SALT scores were calculated for each patient on the day of study enrollment. Patients were stratified by SALT score into severity subclasses S1 (0%-24%), S2 (25%-49%), S3 (50%-74%), S4 (75%-99%), and S5 (100%). Medical records were reviewed for patient demographic characteristics and date of diagnosis. Data were de-identified and stored in REDCap, a secure, HIPPA (Health Insurance Portability and Accountability Act)-compliant online database. This study was approved by the institutional review board of each participating institution.

Questionnaire completion

One parent per patient completed 2 surveys: the Quality of Life in a Child's Chronic Disease Questionnaire (QLCCDQ), which measures QoL in parents of children with general chronic disease, and the Family Dermatology Life Quality Index (FDLQI), a QoL index specific to dermatology. The same parent also completed a 4-question demographic data questionnaire. Children >7 years of age or with appropriate reading and cognitive abilities were invited to complete the Children's Dermatologic Life Quality Index (CDLQI).

During the visit, SALT scores were calculated by an investigator and recorded. Medical records were reviewed for patient demographic data, age at time of enrollment, and duration of time since disease onset.

Abbreviations used:

AA:	alopecia areata
AT:	alopecia totalis
AU:	alopecia universalis
CDLQI:	Children's Dermatology Life Quality Index
FDLQI:	Family Dermatology Life Quality Index
QLCCDQ:	Quality of Life in Chronic Child's Disease Questionnaire
QoL:	quality of life
SALT:	Severity of Alopecia Tool
SD:	standard deviation

QoL instruments

Quality of life in a child's chronic disease questionnaire. The QLCCDQ is a 15-item general chronic illness QoL questionnaire that was validated in a 98-participant study with robust internal consistency (Cronbach alpha 0.77), reliability, and reproducibility (kappa coefficient 0.61-0.80).⁸ Responses to each item are based on a Likert scale from 1 (most bothered or limited) to 7 (not bothered or limited). Responses concern parental perceptions over the prior 2 weeks. This questionnaire was designed to target 3 different components of QoL referred to as the domains emotional (4 questions), parent's perception of child's symptoms (3 questions), and role limitations, including social (3 questions), occupational (3 questions), and family (2 questions). The emotional domain assesses parents' feelings of depression or anxiety as a result of their child's disease, as well as worries or concerns about their child's future. Family role limitations includes limited time spent with other family members as well as on daily household activities. Occupational role limitations evaluates any decrease in work-related activities. Last, social role limitations encompasses a decrease in the parent's social interactions due to their child's disease. In our study, scores on the QLCCDQ are reported as an average per item (0-7 points) as well as averages (0-7) for each domain. Lower QLCCDQ scores represent greater impairment in QoL.

Family dermatology life quality index. The FDLQI is a commonly used and well validated 10-item questionnaire measuring the impact of skin diseases on families of affected patients. The FDLQI had high internal consistency (Cronbach alpha 0.88) and test-retest reliability (intraclass correlation coefficient 0.94) in a 132-person validation study.¹⁰ Scores on the FDLQI are reported as a sum total out of 30 possible points, with higher scores representing greater impairment in QoL.

Children's dermatologic life quality index. The CDLQI is a 10-item questionnaire that has shown

Table I. Characteristics of patient participants with alopecia areata, alopecia totalis, and alopecia universalis

Characteristic	Value	Range
Age, y, mean (SD)	11.0 (4.8)	1.4-22.3
SALT score, mean (SD)	38.2 (38.3)	0-100
Duration of disease, mon, mean (SD)	37.8 (38.9)	1.87-182
Self-reported race/ethnicity, n (%)		-
White	86 (56.2)	-
African American or black	28 (18.3)	-
Hispanic/Latino	14 (9.2)	-
Asian	9 (5.9)	-
Indian	3 (2.0)	-
Other*	13 (8.4)	-

SALT, Severity of Alopecia Tool; SD, standard deviation.

*Other category includes Native Hawaiian or other Pacific Islander, Native American or Alaska native, and unspecified.

acceptable test-retest reliability in a 233-person validation study. CDLQI scores are reported as a sum total out of 30 possible points, with higher scores representing greater impairment in a child's QoL. The CDLQI has demonstrated high repeatability (Cronbach alpha 0.85).¹¹

Statistical analyses

Spearman rank correlations were used to observe the association between QoL scores with severity of disease, duration of disease, and patient age. Statistical significance was defined as a *P* value <.05. All statistical analyses were conducted using Stata/IC version 15.

RESULTS

Patient characteristics

A total of 153 patients were included in this study. The mean age was 11.0 (range 1.4-22.3) years, and female-to-male ratio was 1.3:1. Average SALT scores at time of parent survey completion were 38.2 (standard deviation [SD] 38.3), ranging from 0%-100% (Table I). In our patient cohort, 54% had mild disease, 24.9% had moderate disease, and 28.1% had severe disease.

Of all 153 patients, 47 completed the CDLQI. The average overall score was 4.4 (range 0-22, SD 4.9). Items that most frequently elicited a response indicating QoL impairment (ie, per-item score >0 or not at all) were questions 1 and 2, which ask about physical symptoms and embarrassment or self-consciousness, respectively.

Table II. Summary of quality of life survey results, by alopecia severity subgroup

Patient or parent grouping	N (%)	Mean FDLQI overall score \pm SD	QLCCDQ score, mean \pm SD					Symptom perception domain
			Per-item	Emotional domain	Occupational roles domain	Social roles domain	Family roles domain	
S1	79 (51.6)	5.3 \pm 4.3	5.9 \pm 0.91	5.0 \pm 1.5	6.6 \pm 0.75	6.6 \pm 0.76	6.7 \pm 0.59	5.5 \pm 1.5
S2	16 (10.4)	7.6 \pm 5.3	5.6 \pm 1.1	4.6 \pm 1.6	6.7 \pm 0.63	6.5 \pm 0.89	6.7 \pm 0.57	4.7 \pm 2.3
S3	10 (6.5)	7.2 \pm 6.3	5.1 \pm 0.92	3.7 \pm 1.2	5.7 \pm 1.1	6.2 \pm 1.1	6.15 \pm 0.97	4.4 \pm 1.3
S4	22 (14.3)	6.3 \pm 4.7	5.8 \pm 0.69	4.7 \pm 1.1	6.4 \pm 0.87	6.5 \pm 0.73	6.75 \pm 0.50	5.5 \pm 1.1
S5	19 (12.4)	10.3 \pm 7.1	4.9 \pm 1.6	3.7 \pm 1.7	5.7 \pm 1.5	5.6 \pm 1.9	5.76 \pm 1.8	4.5 \pm 2.1
Overall	153	6.5 \pm 5.3	5.7 \pm 1.1	4.6 \pm 1.5	6.4 \pm 0.96	6.4 \pm 1.1	6.53 \pm 0.92	5.2 \pm 1.7

FDLQI, Family Dermatology Life Quality Index; QLCCDQ, Quality of Life in Chronic Child's Disease Questionnaire; SD, standard deviation.

Parent characteristics

In parent participants, the female-to-male ratio was 3:1, and average age was 41.5 (SD 8.0) years; 37.1% of parents had an undergraduate degree (highest level of education), 30.5% held a graduate degree, 26.7% held a high school diploma, and 5.7% had not completed high school. Most parents (81.6%) reported raising their child with AA, AT, or AU in a dual-parent household, and the remaining 18.4% were either single parents or 2-household families.

Descriptive results for the FDLQI and QLCCDQ completed by parent participants are shown in Table II.

Statistically significant negative correlations were found between SALT scores and QLCCDQ per-item scores and between SALT scores and QLCCDQ emotional domain scores (Table III). A statistically significant positive correlation was found between SALT scores and FDLQI scores. Duration of disease showed a significant negative correlation with QLCCDQ emotional domain scores but no significant correlation with either average per-item QLCCDQ scores or overall FDLQI scores. Age of child correlated negatively with QLCCDQ per-item and emotional domain scores, but the relationship between age and FDLQI scores did not reach statistical significance.

DISCUSSION

In this study, we describe and evaluate the QoL of parents of patients with AA, AT, and AU. FDLQI scores for parents of children with AA (6.5, Table II) were lower than those reported in parents of children with atopic dermatitis (13.6-17) and lower but within range of scores reported in psoriasis parents (8.8).^{7,12,13} Using QLCCDQ scores, we found an impairment in parents' QoL that was predominantly emotional. On average, QLCCDQ emotional domain scores (4.6) were similar to those reported in

Table III. Correlations between parent quality of life measures and severity of disease, duration of disease, and age of child with alopecia areata, alopecia totalis, and alopecia universalis

Category	QLCCDQ score		
	FDLQI overall score	Per-item	Emotional domain
SALT score	0.29 (<.001)*	-0.28 (.001)*	-0.32 (<.001)*
Duration of disease	0.06 (.459)	-0.15 (.064)	-0.16 (.049)*
Age of child	-0.03 (.723)	-0.27 (.001)*	-0.18 (.030)*

Values provided are Spearman rho (*P* value).

FDLQI, Family Dermatology Life Quality Index; QLCCDQ, Quality of Life in Chronic Child's Disease Questionnaire; SALT, Severity of Alopecia Tool.

*Statistically significant (*P* < .05).

parents of children with stable, chronic medical disease (4.5), such as type I diabetes and asthma.⁸

Previous work examining the impact of AA on QoL did not indicate a relationship between severity of disease and QoL but suggested that poorer QoL is associated with increasing age of the affected individuals.⁵ Our study adds to the findings of earlier QoL research by showing that overall and emotional QoL of the parent decreases with increasing disease severity and age of the affected child (Table III).

We found no significant correlation between duration of disease and overall parental QoL, and despite reaching statistical significance, emotional QoL impairment correlated only slightly (ie, Spearman rho <0.2) with duration of disease (Table III, Spearman rho -0.16, *P* = .049). These findings suggest that the challenges parents face do not diminish, even as parents might undergo psychological adjustment to a child's diagnosis over time.

Patient age correlated with overall parental QoL scores on the QLCCDQ but not on the FDLQI (Table III). The relationship between patient age and parental scores on these instruments has not

been previously described, and it is possible that the QLCCDQ is more sensitive to age-related QoL impairment. Despite reaching statistical significance, only a slight correlation existed between patient age and emotional QoL of parents (Table III, Spearman rho -0.18 , $P = .030$). Thus, our results suggest that while overall parental QoL might decrease as children age, emotional QoL might be more closely related to severity of disease than either age of the child or duration of disease.

Our study is limited by its small sample size and cross-sectional design. In addition, factors which we did not or could not account for might play a significant role in parental QoL, such as social support and whether the child was improving or worsening at the time of survey completion. We did not ask parents at the time of the survey if the child was experiencing a period of hair regrowth, hair loss (flare), or stable disease, nor were we able to determine this through retrospective review, given that AA can flare and remit in the time interval between visits.

Despite its limitations, this study is the first to describe QoL of parents, rather than family members in general, of patients with AA. Our inclusion of the QLCCDQ offers a more targeted investigation than using only the FDLQI would allow; the QLCCDQ was developed for parents, and the FDLQI is intended for broad use in any first-degree family member of affected patients.¹⁰ This disparity in intended use might partly explain why the FDLQI and QLCCDQ scores correlated moderately in our study ($r = -0.64$). In addition, the domain-based approach of the QLCCDQ enables us to evaluate particular components of overall QoL. An important strength which sets our study apart from Liu et al⁵ is that our sample, though limited in size, is highly representative of the greater population of patients with AA, AT, and AU and their parents. Data for this study were collected in a clinical setting free of the selection bias that might exist when a convenience sample is used, such as participants who are recruited through national foundations or support groups.

Treatment of pediatric populations is unique; primary caregivers act as crucial liaisons between physicians and patients, creating a need for caregiver-oriented patient care. In that regard, the clinical implications of our study's results are far-reaching. First, it is crucial for providers to be aware that the severity of disease predicts parental QoL impairment, but only to some extent, so that we are careful not to neglect the counseling and education that is warranted in families facing milder

disease in addition to those dealing with severe disease. Second, acknowledging that the greatest impairment in parents' QoL is emotional should inform patient encounters and prompt providers to tailor counseling accordingly. Such adjustments during clinic visits could include asking parents about how the disease has affected them and providing coping strategies such as support group information or additional educational resources. Third, the finding that parents might experience greater impairment in overall wellbeing as children age can be used to help parents set realistic expectations for long-term prognosis and course of the disease.

Further parent-centered QoL research is needed, given that caregiver QoL and perception of a child's symptoms play an important role in controlling chronic disease in children.^{14,15} Moreover, given our finding that emotional QoL scores were most affected by AA, there might be a need for more stigma-focused QoL instruments as well as surveys designed for use in parents or patients dealing with hair disorders, which often present different psychosocial and functional challenges than skin-limited disease.

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