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Measurement instruments to assess quality of life in pediatric patients with alopecia areata: A systematic review

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Introduction & Objectives:

The unpredictability of alopecia areata (AA), an immune-mediated hair loss disorder, and its visual clinical manifestations can severely impact emotional well-being, peer interactions, and overall quality of life (QoL) in pediatric patients.1,2 As a result, assessing QoL in pediatric patients with AA is crucial for understanding and guiding management. Despite the importance of assessing QoL in this demographic, no consensus exists on the most appropriate measurement tool. Existing tools, such as the Children's Dermatology Life Quality Index (CDLQI), address aspects of QoL including social and emotional well-being, however, they are more representative of QoL in dermatological conditions with common physical symptoms (e.g., pain or pruritus) such as atopic dermatitis or psoriasis.3,4 Herein, this systematic review aims to analyze QoL instruments in pediatric AA, evaluating their comprehensiveness and applicability, with the goal of better understanding pediatric AA QoL through measurement instruments.

Materials & Methods:

MEDLINE, Embase, Scopus and Web of Science were searched from inception to September 2024, using keywords related to AA, pediatrics, and QoL per PRISMA guidelines and registered in PROSPERO (CRD42024590495).5 Peer-reviewed studies reporting on QoL in pediatric AA in English were included. Excluded studies included abstracts and those not used in pediatric AA. Study quality was assessed using the Joanna Briggs Institute critical appraisal tool.

Results:

We identified 12 studies comprising 18 QoL instruments used in pediatric AA, with only two (11.1%) being AA specific. All were validated in pediatric populations, and 44.4% (8/18) were used exclusively in pediatric age groups. Most study data was self-reported (66.7%, 12/18), by proxy (27.8%, 5/18), or self/proxy (5.56%, 1/18). CDLQI was the most frequent instrument used (58.3%, 7/12 studies).

Each of the 10 domains assessed by pediatric AA QoL instruments and their characteristics are outlined in Table 1. Studies addressed between 1 to 8 of the domains assessed (median: 3). Other validated QoL tools, such as the Hairdex, were not included in this study due to their limited previous use in pediatric populations.

Conclusion:

The heterogeneity in domains by this cohort suggests a lack of consensus on the most critical aspects of QoL to measure in pediatric AA, potentially leading to inconsistencies in reported QoL outcomes. The literature also highlights a reliance on generic QoL instruments, including those best suited for anxiety and depression, and a gap of these instruments validated for use in AA.

Future pediatric AA QoL instruments need to achieve comprehensive coverage of domains to ensure that all dimensions of a child's life affected by AA are considered. The inclusion of domains such as workplace functioning

and romantic relationships which may be relevant to older adolescents. Collaboration from parents, and professionals in mental health, pediatrics, and dermatology will aid in the accurate assessment of these dimensions. Future instruments should integrate both self-reported and proxy-reported measures, allowing for insights from both children and caregivers. Limitations of this review include the exclusion of non-English language studies, which may limit the generalizability of the findings.

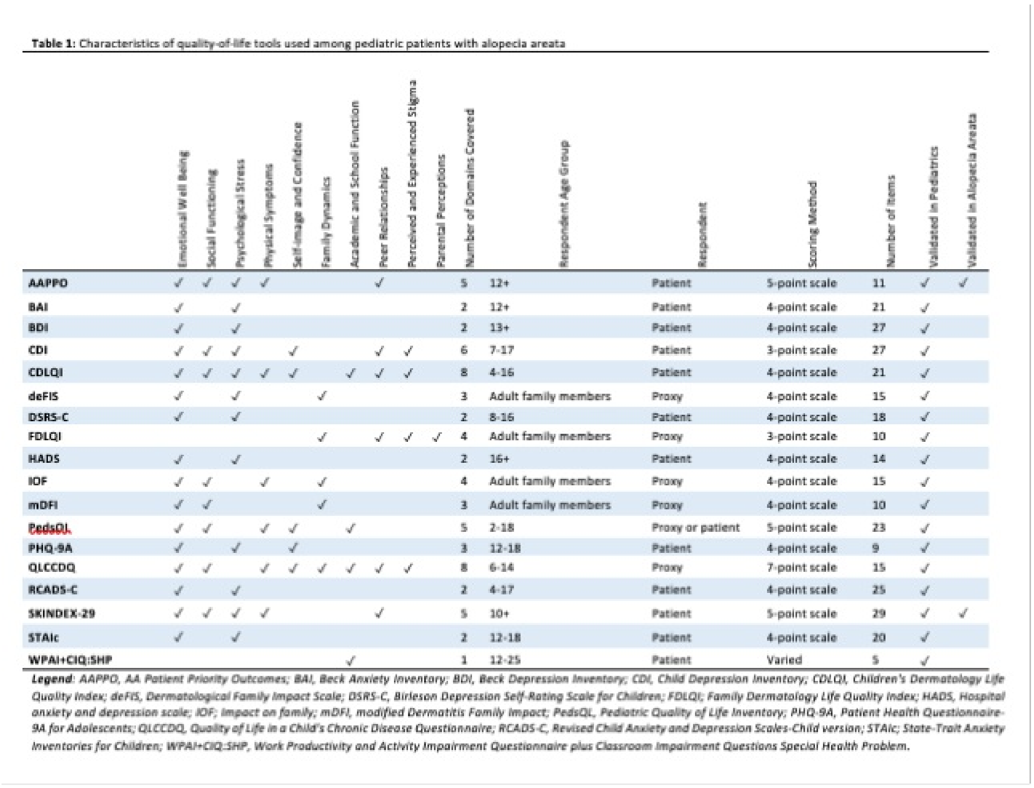

Table 1: Characteristics of quality-of-life tools used among pediatric patients with alopecia areata

	Emotional Well Being	Social Functioning	Psychological Stress	Physical Symptoms	Self-image and Confidence	Family Dynamics	Academic and School Function	Peer Relationships	Perceived and Experienced Stigma	Parental Perceptions	Number of Domains Covered	Respondent Age Group	Respondent	Scoring Method	Number of Items	Validated in Pediatrics	Validated in Alopecia Areata
AAPPO	✓	✓	✓	✓				✓			5	12+	Patient	5-point scale	11	✓	✓
BAI	✓		✓								2	12+	Patient	4-point scale	21	✓	
BDI	✓		✓								2	13+	Patient	4-point scale	27	✓	
CDI	✓	✓	✓		✓			✓	✓		6	7-17	Patient	3-point scale	27	✓	
CDLQI	✓	✓	✓	✓	✓		✓	✓	✓		8	4-16	Patient	4-point scale	21	✓	
deFIS	✓		✓			✓					3	Adult family members	Proxy	4-point scale	15	✓	
DSRS-C	✓		✓								2	8-16	Patient	4-point scale	18	✓	
FDLQI						✓		✓	✓	✓	4	Adult family members	Proxy	3-point scale	10	✓	
HADS	✓		✓								2	16+	Patient	4-point scale	14	✓	
IOF	✓	✓		✓		✓					4	Adult family members	Proxy	4-point scale	15	✓	
mDFI	✓	✓				✓					3	Adult family members	Proxy	4-point scale	10	✓	
PedsQL	✓	✓		✓	✓		✓				5	2-18	Proxy or patient	5-point scale	23	✓	
PHQ-9A	✓		✓		✓						3	12-18	Patient	4-point scale	9	✓	
QLCCDQ	✓	✓		✓	✓	✓	✓	✓	✓		8	6-14	Proxy	7-point scale	15	✓	
RCADS-C	✓		✓								2	4-17	Patient	4-point scale	25	✓	
SKINDEX-29	✓	✓	✓	✓				✓			5	10+	Patient	5-point scale	29	✓	✓
STAIc	✓		✓								2	12-18	Patient	4-point scale	20	✓	
WPAI+CIQ:SHP							✓				1	12-25	Patient	Varied	5	✓	

***Legend**: AAPPO, AA Patient Priority Outcomes; BAI, Beck Anxiety Inventory; BDI, Beck Depression Inventory; CDI, Child Depression Inventory; CDLQI, Children's Dermatology Life Quality Index; deFIS, Dermatological Family Impact Scale; DSRS-C, Birleson Depression Self-Rating Scale for Children; FDLQI; Family Dermatology Life Quality Index; HADS, Hospital anxiety and depression scale; IOF; Impact on family; mDFI, modified Dermatitis Family Impact; PedsQL, Pediatric Quality of Life Inventory; PHQ-9A, Patient Health Questionnaire-9A for Adolescents; QLCCDQ, Quality of Life in a Child's Chronic Disease Questionnaire; RCADS-C, Revised Child Anxiety and Depression Scales-Child version; STAIc; State-Trait Anxiety Inventories for Children; WPAI+CIQ:SHP, Work Productivity and Activity Impairment Questionnaire plus Classroom Impairment Questions Special Health Problem.*