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EM-91228 March 2022

## POSITION STATEMENT

# Quality of life measurement in alopecia areata. Position statement of the European Academy of Dermatology and Venereology Task Force on Quality of Life and Patient Oriented Outcomes

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## Abstract

New treatment options may lead to an increased interest in using reliable and sensitive instruments to assess health-related quality of life in people with alopecia areata (AA). The purpose of this paper is to present current knowledge about quality of life assessment in AA. The dermatology-specific Dermatology Life Quality Index (DLQI) was the most widely reported health-related quality of life instrument used in AA. Three AA-specific (Alopecia Areata Symptom Impact Scale, Alopecia Areata Quality of Life Index and Alopecia Areata Patients' Quality of Life) and three hair disease-specific instruments (Hairdex, Scalpdex and 'hair-specific Skindex-29') were identified with a range of content and validation characteristics: there is little evidence yet of the actual use of these measures in AA. Scalpdex is the best-validated hair disease-specific instrument. Further extensive validation is needed for all of the AA-specific instruments. The European Academy of Dermatology and Venereology Task Force on Quality of Life and Patient Oriented Outcomes recommends the use of the dermatology-specific DLQI questionnaire, hair disease-specific Scalpdex and the alopecia areata-specific instruments the Alopecia Areata Symptom Impact Scale or Alopecia Areata Quality of Life Index, despite the limited experience of their use. We hope that new treatment methods will be able to improve both clinical signs and health-related quality of life in patients with AA. In order to assess the outcomes of trials on these new treatment methods, it

would be helpful when further development and validation of AA-specific instruments is being encouraged and also conducted.

Received: 16 February 2021; Accepted: 28 April 2021

### Conflict of interest

AYF is joint copyright owner of the DLQI, CDLQI, IDQoL, DFI and FDLQI and other quality of life measures: Cardiff University and AYF receive royalties from the use of these measures. AYF has received honoraria for advisory boards: Novartis, USB Pharma. GBEJ has received honoraria from AbbVie, Chemocentryx, Coloplast, Incyte, Inflarx, Kymera, Leo Pharma, Novartis and UCB for participation on advisory boards, and grants from AbbVie, Astra-Zeneca, Inflarx, Janssen-Cilag, Leo Pharma, Novartis, Regeneron and Sanofi, for participation as an investigator, and received speaker honoraria from AbbVie, Boehringer Ingelheim, Galderma and Novartis. He has also received unrestricted departmental grants from Leo Pharma and Novartis. CB has received speaker honoraria, research grants, awards and/or travel expenses from Celgene, Janssen-Cilag, Kreussler, Lilly, Mapi Group, medi, Stiefel Laboratories, the EuroQoL Group and Urgo. JCS served as a consultant and advisor for AbbVie, Leo Pharma, Novartis, Menlo, Pierre-Fabre, Sienna Pharmaceuticals and Trevi and investigator for AbbVie, Amgen, Janssen, Merck, Novartis, Regeneron and Trevi. JCS served as a consultant and advisor for AbbVie, Leo Pharma, Novartis, Menlo, Pierre-Fabre, Sienna Pharmaceuticals and Trevi, investigator for AbbVie, Amgen, Janssen, Merck, Novartis, Regeneron, Trevi, Boehringer Ingelheim, Galapagos, InflaRX, Pfizer, UCB, Incyte, Helm, Janssen, Menlo Therapeutics; Speaker for AbbVie, Janssen, Leo Pharma, Novartis, Sun-Farm, Eli Lilly and Sanofi-Genzyme. FS reports personal fees from AbbVie, outside the submitted work. CS reports non-financial support from Leo Pharma, grants from CeraVe International, outside the submitted work. AB reports personal fees from AbbVie, personal fees from Almirall, personal fees from Galderma, personal fees from Eli Lilly, personal fees from Janssen, personal fees from Leo Pharma, personal fees from Novartis, personal fees from Sanofi, personal fees from UCB, outside the submitted work. Other authors reported no conflicts of interests.

### Funding source

None.

## Introduction

Alopecia areata (AA) is an autoimmune disease of unknown aetiology. The lifetime incidence of AA is approximately 2% worldwide. The AA prevalence is higher in children than in adults, is increasing over time and significantly differs by geographical region but does not differ significantly between genders. The earlier the age of first onset, the greater the lifetime risk of extensive disease. Diagnosing AA can be made on the basis of the history and clinical findings. Patients will often present with patchy, non-scarring hair loss generally affecting the scalp.<sup>1–3</sup>

The role of hair in human societies is primarily psycho-social. This was corroborated by a systematic review with meta-analysis<sup>4</sup> that concluded that patients with AA experience significant impairment in health-related quality of life (HRQoL), especially in the area of mental health. Several generic and dermatology-specific HRQoL instruments have been used, but no validation studies have confirmed their applicability in AA. The newly developed AA-specific measures seem promising; however, a more extensive assessment of validity and reliability is needed.<sup>4</sup>

The discovery of Janus kinase (JAK) inhibition represents a major breakthrough in the treatment of AA. Positive results in

early-phase clinical trials have enabled the commencement of phase 3 clinical trials, and they might become the first FDA-approved treatment for alopecia areata.<sup>5–7</sup>

With patient-reported outcome (PRO) measures attracting increasing attention from both the EMA and the FDA, identifying reliable and sensitive instruments of HRQoL assessment for use in AA patients is essential.

For many reasons, it is therefore important to review the instruments available for HRQoL assessment in AA, including data on AA-specific and hair disease-specific HRQoL instruments and HRQoL changes in clinical trials, and to make practical recommendations concerning the assessment of QoL in people with AA.

## Methods

This present paper is organized by the European Academy of Dermatology and Venereology (EADV) Task Force (TF) on QoL and Patient Oriented Outcomes, which has previously presented detailed recommendations on principles of HRQoL instrument selection and use in different skin diseases.<sup>8–19</sup> Members of the TF were invited to participate. A literature search was performed using the PubMed database, which was searched from 1980 to October 2020 using the keyword combination: 'quality of life,

alopecia areata'. All those who volunteered were allocated a section of the identified articles to review.

Inclusion criteria:

All identified publications written in English or those having English abstracts were considered.

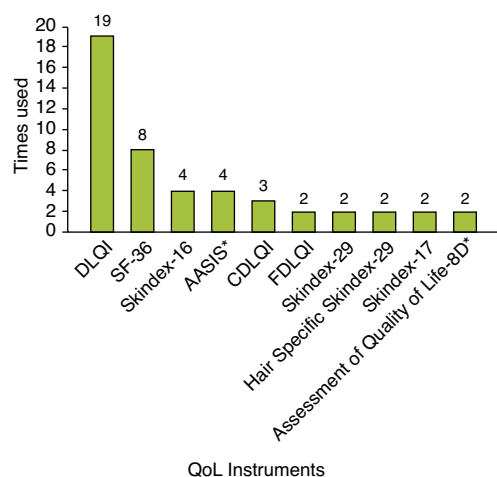
Exclusion criteria:

- Review articles, guidelines, protocols.
- Studies without HRQoL assessment.
- Measurement of HRQoL in conditions other than AA.
- Studies where HRQoL was studied in AA and other diseases but results on AA were not presented and/or discussed separately.

All publications were independently assessed by two co-authors. Exceptions were made for articles with non-English full text: in those cases, the assessment was made by one co-author. The results of literature search assessments were compared and discrepancies discussed and resolved. The remaining publications were analysed in detail, and the QoL instruments used in AA were listed. The EADV TF on QoL and Patient Oriented Outcomes recommends using the word 'quimp'<sup>20</sup> (quality of life impairment) in routine clinical work and research,<sup>21</sup> and the word has been used in this article.

## Results

From the 134 articles identified in the literature search, 86 were excluded based on the exclusion criteria, leaving 48 publications<sup>22–69</sup> for the final analysis (Table S1). Twenty-five different HRQoL instruments were used for HRQoL assessment of patents in these 48 publications. Ten instruments were used more than once (Fig. 1). The most frequently used instrument



**Figure 1** How many times health-related quality of life (HRQoL) instruments were used in alopecia areata. \* Probably these two publications<sup>63,64</sup> appear to describe the same study.

was the Dermatology Life Quality Index (DLQI).<sup>70</sup> Fifteen other instruments were used only in one publication each.

There were several different reasons that HRQoL in AA was studied, including to investigate specific issues of HRQoL impairment in AA patients, to compare HRQoL in patients with AA and controls, or HRQoL in patients with AA and other diseases, and to assess HRQoL in different age groups or between genders. In addition, HRQoL instruments were used as outcome measures in clinical trials and in the development and validation of AA-specific HRQoL instruments.

### Peculiarities of HRQoL impairment in AA patients

In the study by Willemse *et al.*,<sup>54</sup> 86% of people with AA had at least some HRQoL impairment. Groups of patients with severe AA,<sup>30,52,57</sup> with alopecia totalis/alopecia universalis,<sup>40</sup> with hair loss for over 12 months,<sup>52,67</sup> experiencing long duration, experiencing recurrent disease<sup>40</sup> or having nail changes and concomitant autoimmune disease<sup>67</sup> all had worse HRQoL. The AA patients with depression, when compared to those without, had significantly worse HRQoL in the domains of daily activities, leisure, work or school, personal relationships and emotions, and social functioning.<sup>43</sup>

**HRQoL in patients with AA and controls** The AA patients had worse HRQoL than controls.<sup>36,44,65</sup> Of the eight SF-36 subscales, vitality and mental health scores were higher (better QoL) in the control group, whereas social functioning scores were higher in the patients.<sup>22</sup> According to parental assessment, children with AA apparently had worse HRQoL than controls, but there was no difference in the children's own self-assessment scores.<sup>37</sup>

**HRQoL in patients with AA and other diseases** Two studies found no significant differences in HRQoL impairment between AA, androgenetic alopecia and telogen effluvium.<sup>28,60</sup> One study found more impaired HRQoL in androgenetic alopecia than in AA patients<sup>45</sup> but two other studies reported the opposite.<sup>46,65</sup> In two studies, some HRQoL aspects were more impaired in people with AA, and other aspects were more impaired in people with androgenetic alopecia.<sup>56,58</sup> However, total Hairdex scores were higher in patients with androgenetic alopecia and there was no difference in the Turkish Quality of Life instrument (TQL) scores between AA and androgenetic alopecia.<sup>58</sup>

When compared to people with psoriasis, chronic idiopathic urticaria and atopic dermatitis, people with AA reported significantly better mood, leisure activity, daily life and physical discomfort scores and worse scores for self-perception. People with AA were less bothered by treatment-induced restrictions than those with psoriasis, but more bothered than those with chronic idiopathic urticaria. The AA patients reported significantly better HRQoL than did hidradenitis suppurativa patients, except for the social functioning and mental health dimensions of SF-36 and self-perception, mood state and treatment restriction

dimensions of VQ-Dermato.<sup>26</sup> Overall, HRQoL in the AA patients was better than those with psoriasis, urticaria, acne and atopic dermatitis.<sup>32,44,48</sup>

**HRQoL in different age groups** Health-related quality of life was studied in different age groups of children with AA and was more impaired in 5- to 11-year-old patients than in those aged 12–14 and 15–19 years.<sup>49</sup> The HRQoL of adult family members of children with AA was more impaired than the HRQoL of adult family members of adults with AA.<sup>55</sup>

**Gender differences** Several studies have reported no significant differences in HRQoL scores between male and female patients.<sup>50,60,66</sup> However, one study showed that the HRQoL of female patients with AA was more impaired than that of male patients.<sup>57</sup> Another study showed that compared to men, women were significantly more likely to report feeling frustrated and embarrassed and feeling as if they had lost something.<sup>62</sup>

**Clinical trials** We identified eight reports of clinical trials in AA. Two publications reported significant improvement in HRQoL following hypnotherapy but without improvement of hair growth.<sup>25,27</sup> Two more publications reported HRQoL improvement in AA patients who have had good treatment results, with pulsed corticosteroid therapy<sup>33</sup> and with tofacitinib.<sup>50</sup> No significant improvement of HRQoL in AA patients was reported in studies using cyclosporine<sup>63,64</sup> or IL-2,<sup>69</sup> and worsening of

HRQoL was reported in a study of the (no longer licensed) drug efalizumab.<sup>23</sup>

Wigs or hairpieces improved perceived competence, adaptability and self-esteem, and such effects correlated with the extent of satisfaction with appearance using wigs.<sup>35</sup>

**Development and validation of AA-specific HRQoL instruments** We identified three AA-specific HRQoL instruments: Alopecia Areata Symptom Impact Scale (AASIS),<sup>39,51,53,64</sup> Alopecia Areata Quality of Life Index (AA-QLI)<sup>31,47</sup> and Alopecia Areata Patients' Quality of Life (AAQ).<sup>30</sup> The AASIS contains three AA-specific items, all related to signs and symptoms: scalp hair loss; body or eyelashes hair loss; and tingling/numbness of the scalp. The AA-QLI contains six AA-specific items: 'feel uncomfortable using a wig'; 'tend to hide my scalp with hats or bandanas'; 'do not take my wig/hat/bandana off in front of my partner/relatives/friends'; 'my scalp is visible'; 'lose tufts of hair when comb or shampoo'; and 'feel itchy on my scalp'. The AAQ contains a single AA-specific item: 'it takes longer to arrange my appearance, for example to put on wig'. Details of these AA-specific HRQoL instruments and hair disease-specific HRQoL instruments are given in Table 1.

## Discussion

Most of the studies identified showed that the HRQoL of AA patients is worse than that of the general population. Patients with a history of severe AA, long disease duration, recurrent hair

**Table 1** Information on alopecia areata (AA)-specific and hair disease-specific health-related quality of life (HRQoL) instruments

Name	Short name/ abbreviation	Number of items	Number of scales	Recall period	Scoring	Validation
<b>AA-specific HRQoL instruments</b>						
Alopecia Areata Patients' Quality of Life <sup>30</sup>	AAQ	7 items	3 subscales: 'restriction of activity', 'concealment' and 'adaptation'	Last month	Five-point scale ranging from 0 (not at all) to 4 (very much)	Construct validity, internal consistency, convergent validity
Alopecia Areata Quality of Life Index <sup>31</sup>	AA-QLI	21 items	3 subscales: 'subjective symptoms', 'relationship', and 'objective signs'	Last month	Scored from 1 (not affected at all) to 4 (highly affected)	Convergent validity
Alopecia Areata Symptom Impact Scale <sup>39</sup>	AASIS	13 items	3 subscales: 'impact of AA', 'hair loss', and 'physical skin symptoms'	Past week	Visual analog scale from 0 to 10	Internal consistency
<b>Hair disease-specific HRQoL instruments</b>						
Hairdex <sup>79</sup>	–	48 items	5 subscales: 'emotions', 'functioning', 'symptoms', 'self-confidence' and 'stigmatization'	Not stated	Scored from 0 (never) to 4 (all the time)	Internal consistency, convergent validity, factor analysis
The hair-specific Skindex-29 <sup>80</sup>	–	29 items	3 scales: 'symptoms', 'emotions' and 'functioning'	Past 4 weeks	Scored from 0 (never) to 4 (all the time)	No data on validation The words 'skin' and 'skin condition' on the Skindex-29 were changed to 'scalp' or 'alopecia'
Scalpdex <sup>81</sup>	–	23 items	3 scales: 'symptoms', 'emotions' and 'functioning'	Past 4 weeks	Scored from 0 (never) to 4 (all the time)	Internal consistency, convergent validity, test-retest reliability, responsiveness

loss episodes or comorbidities experienced even greater impact on HRQoL. However, it seems that AA impacts HRQoL less than most other skin diseases, except that impact on self-perception is comparable with that caused by androgenetic alopecia and telogen effluvium. On a large sample of patients with 32 skin diseases, those with AA ranked as the 22nd most severely impacted according to the Skindex-17 scores.<sup>71</sup> The HRQoL in 3- to 4-year-old children with AA was better than in children with epidermolysis bullosa, atopic dermatitis, urticaria and molluscum contagiosum as measured by the InToDermQoL questionnaire.<sup>72</sup> HRQoL of younger children with AA and their family members is more impaired than in older children and in family members of adults with AA.<sup>49,55</sup> The problem of lack of concordance between the reporting of HRQoL impact of AA by children themselves and by adults on their behalf<sup>37</sup> has also been reported in other skin diseases. It is therefore recommended to obtain information both from parents and from children whenever possible.<sup>73</sup>

Interpretation of data on gender differences in patients with AA is controversial, as in many other chronic skin diseases. However, it seems that female patients tend to experience a greater HRQoL impact than males. To confirm this and to remove confounding factors, it would be necessary to undertake large population studies or at least studies where participants are well matched by factors other than gender.<sup>74,75</sup>

Clinical trials of cyclosporine, IL-2, efalizumab, pulsed corticosteroid therapy and tofacitinib have either demonstrated no HRQoL improvement<sup>23,63,64,69</sup> or HRQoL improvement only in patients in whom there was good clinical response.<sup>33,50</sup> Significant HRQoL improvement was reported after hypnotherapy<sup>25,27</sup> and with the use of wigs or hairpieces<sup>35</sup> but, of course, without improvement of clinical symptoms.

Some authors<sup>31,39</sup> have suggested that the reports of HRQoL being little affected in patients with AA reflects the low sensitivity for AA-specific issues of the generic instruments used. These critics have pointed out that hair disease-specific instruments and especially AA-specific instruments are likely to be more sensitive than generic instruments in this condition. For example, the use of Hairdex, a hair disease-specific HRQoL instrument, has distinguished differences in HRQoL between patients with AA and those with androgenetic alopecia, when there was no difference identified by the generic TQL questionnaire.<sup>58</sup> The challenge of how to select appropriate HRQoL questionnaires is especially pertinent when planning clinical trials, such as to confirm the efficacy in AA of novel treatment methods, for example JAK inhibitors.

There is currently much attention being given to the concept of identifying and promoting core outcome measure sets, including HRQoL measures, for use across all clinical studies of particular conditions.<sup>76</sup> Often none of the existing HRQoL instruments are considered to be ideal and the selection process to choose measures for core outcome measurement sets should utilize the highest quality methodology, including taking steps to minimize bias.<sup>77</sup>

We identified three AA-specific instruments, that is AASIS, AA-QLI and AAQ: these were the same as those identified in the review by Rencz *et al.* in 2016.<sup>4</sup> However, since then, there has been a validation study<sup>53</sup> of AASIS and AASIS has subsequently been used in a study on willingness to pay<sup>51</sup> and in a clinical trial on the impact of cyclosporine.<sup>64</sup> The AA-QLI has also been used since the Rencz review, in a study on mindfulness-based interventions.<sup>47</sup> No new studies were found for the third AA-specific HRQoL instrument, the AAQ.

The lengths of all three AA-specific HRQoL instruments are acceptable for clinical use. The shorter recall period of the AASIS may result in it being more sensitive for use in clinical trials. The AASIS and the AA-QLI include items on signs and symptoms, and they are therefore composite measures with greater components of PROs, which makes them more reflective of patient experience than measures based solely on signs and symptoms. However, this may result in score changes even in patients who have only objective and subjective symptoms but with no impact on daily routine, communication with others, work or other aspects of daily life. In a study from Korea, only 14% patients with AA reported itching.<sup>78</sup> Itch in AA patients may be attributed to side-effects of different topical treatments, at least in some cases. Wearing wigs or hairpieces could also be a cause. The presence of only a single separate item on HRQoL in the AASIS may lead to speculation that its authors intended to contrast this item to the others. However, several other AASIS items address HRQoL concepts. Further extensive validation is needed for all of the AA-specific instruments. Better validation of these instruments could help to increase the reliability of clinical trials of new treatments.

The topics covered by the three AA-specific instruments are not identical. Although the AASIS has been chosen for use in more studies than the AA-QLI, this of course does not imply that it is 'better' than the AA-QLI. The most frequently used HRQoL instrument in the studies on AA was the dermatology-specific measure, the DLQI. Hair disease-specific Scalpdex is better validated than two other hair-specific instruments.

The EADV TF on QoL and Patient Oriented Outcomes recommends that researchers use the dermatology-specific DLQI questionnaire, hair disease-specific Scalpdex and either of the AA-specific instruments, the AASIS or AA-QLI, despite the limited experience of their use. We hope that new treatment methods will be able to improve both clinical signs and HRQoL in patients with AA. In order to assess the outcomes of trials on these new treatment methods, it would be helpful when further development and validation of AA-specific instruments is being encouraged and also conducted.

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### Supporting information

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Information on included references.