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REVIEW ARTICLE

Position Statement

Quality of Life Measurement in Autoimmune Blistering Diseases: Mutual Position Statement of the European Academy of Dermatology and Venereology Task Forces on Quality of Life and Patient Oriented Outcomes and Autoimmune Blistering Diseases

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ABSTRACT

The European Academy of Dermatology and Venereology (EADV) Task Forces (TFs) on Quality of Life (QoL) and Patient Oriented Outcomes and on Autoimmune Bullous Diseases (AIBD) collaborated on a position statement regarding the QoL instruments that could better evaluate the health-related (HR)QoL in different phases of the course of these chronic diseases. Position statements were formed and accepted by voting of all authors. The ability to use a measure that has a validated system to interpret scores and has a known minimal clinical important difference (MCID), such as the Dermatology Life Quality Index (DLQI), is an important aspect when choosing which HRQoL instrument to use. The EADV TFs encourage the use of the DLQI

as a dermatology-specific instrument and Autoimmune Bullous Disease Quality of Life (ABQOL) and Treatment of Autoimmune Bullous Disease Quality of Life (TABQOL) as AIBD-specific instruments for HRQoL assessment in AIBDs. The EADV TFs encourage the use of the oral health-specific instruments Oral Health Impact Profile-14 (OHIP-14) or Chronic Oral Mucosal Disease Questionnaire (COMDQ) in AIBD patients with severe oral involvement. OHIP-14 has fewer items and that may influence the choice for practical use. The EADV TFs encourage the study, where appropriate, of family QoL of AIBD patients by using dermatology-specific family QoL instruments, such as the Family Dermatology Life Quality Index (FDLQI) or general measures such as the Family Reported Outcome Measure (FROM-16). The EADV TFs recommend that HRQoL instruments be used in randomized controlled studies of new therapeutic approaches. The EADV TFs encourage researchers and clinicians to validate and use HRQoL instruments in patients with AIBDs.

1 | Introduction

Autoimmune bullous diseases (AIBD) encompass a spectrum of chronic, relapsing disorders with cutaneous or/and mucosal involvement that affect the Health Related Quality of Life (HRQoL) on multiple levels [1]. These diseases are commonly underdiagnosed or diagnosed with delay, causing long-lasting itch, pain, or discomfort [2–5]. For most of the diseases in the AIBD spectrum, the impact on QoL gets even heavier due to the treatment modalities. At present, no targeted treatment options are approved for AIBD except for rituximab for moderate and severe pemphigus vulgaris, which represents the greatest therapeutic advance for this disease following the introduction of corticosteroids [6]. As such, therapy relies on long-term use of corticosteroids and potentially corticosteroid-sparing agents [7–13]. The short- and long-term side effects of steroid treatment and the immunosuppression caused by the additional agents affect everyday life. Patients typically report that they learn to live with pain and steroids, underlining the fact that AIBD is a life-changing disease for themselves and their families [14]. S2k and S3 guidelines on the management of pemphigus vulgaris/foliaceus, paraneoplastic pemphigus, bullous pemphigoid, linear immunoglobulin (Ig)A disease, mucous membrane pemphigoid, and dermatitis herpetiformis have been initiated by the European Academy of Dermatology and Venereology (EADV) and recommend using HRQoL instruments to evaluate the effectiveness of therapeutic interventions and monitor disease course [7–13].

The EADV Task Forces on QoL and Patient Oriented Outcomes and on AIBD initiated this position statement regarding the QoL instruments that could better evaluate the HRQoL in different phases of these chronic diseases. These measurements are absolutely necessary to illustrate the disease burden and the impact of treatment.

2 | Methods

Members of the EADV Task Forces on QoL and patient oriented outcomes and on AIBD were invited to participate.

A literature search was performed using the PubMed database, which was searched from the beginning to November 2024 using the key word combinations: “pemphigus, quality of life,” “bullous pemphigoid, quality of life,” and “mucous membrane pemphigoid, quality of life” (all fields). All 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 AIBD

Included publications were analyzed in detail and the results are presented below. Data on used QoL instruments, study participants, and main results related to QoL in urticaria for each publication was extracted. In particular, it made it possible to calculate the frequency of the use of different HRQoL instruments. Position statements were formed and accepted by voting of all authors.

3 | Results

The HRQoL instruments identified by the literature search and how often they were used in the studies on AIBD in general, and in pemphigus vulgaris and bullous pemphigoid are presented on Figures 1–3, respectively. The Chronic Oral Mucosal Diseases Questionnaire (COMDQ) and Oral Health Impact Profile (OHIP-14) were used in the studies on mucous membrane pemphigoid [15]. Two AIBD-specific HRQoL instruments, Autoimmune Bullous Disease Quality of Life (ABQOL) [16] and Treatment of Autoimmune Bullous Disease Quality of Life (TABQOL) [17] were identified. The characteristics of both instruments are given in Table 1. The characteristics of the oral-specific HRQoL instruments COMDQ and OHIP-14 are presented in Table 2. A detailed comparison of the content of the AIBD-specific and oral-specific HRQoL instruments is presented in Table S1. The dermatology-specific Dermatology Life Quality Index (DLQI), that has a validated score meaning banding system, was the most frequently used HRQoL instrument in pemphigus vulgaris and bullous pemphigoid. This makes it possible to compare the QoL impact and interpret score meanings between different studies and diseases (Table 3).

Measures of disease clinical severity significantly correlated with scores of the DLQI [25, 27], Skindex-16 [39], OHIP-14 [27], Quality of life instrument for Turkish people with skin disease [27], SF-36, and Skindex-29 [40]. Pain scores correlated with OHIP-14 [41, 42] scores and COMDQ [42]. The change in Pemphigus Disease Area Index (PDAI) showed a strong correlation with changes in the ABQOL and with Skindex-29 symptoms and functioning subscales [43]. The DLQI, ABQOL, and TABQOL scores did not correlate with disease severity in other studies [33, 35, 44].

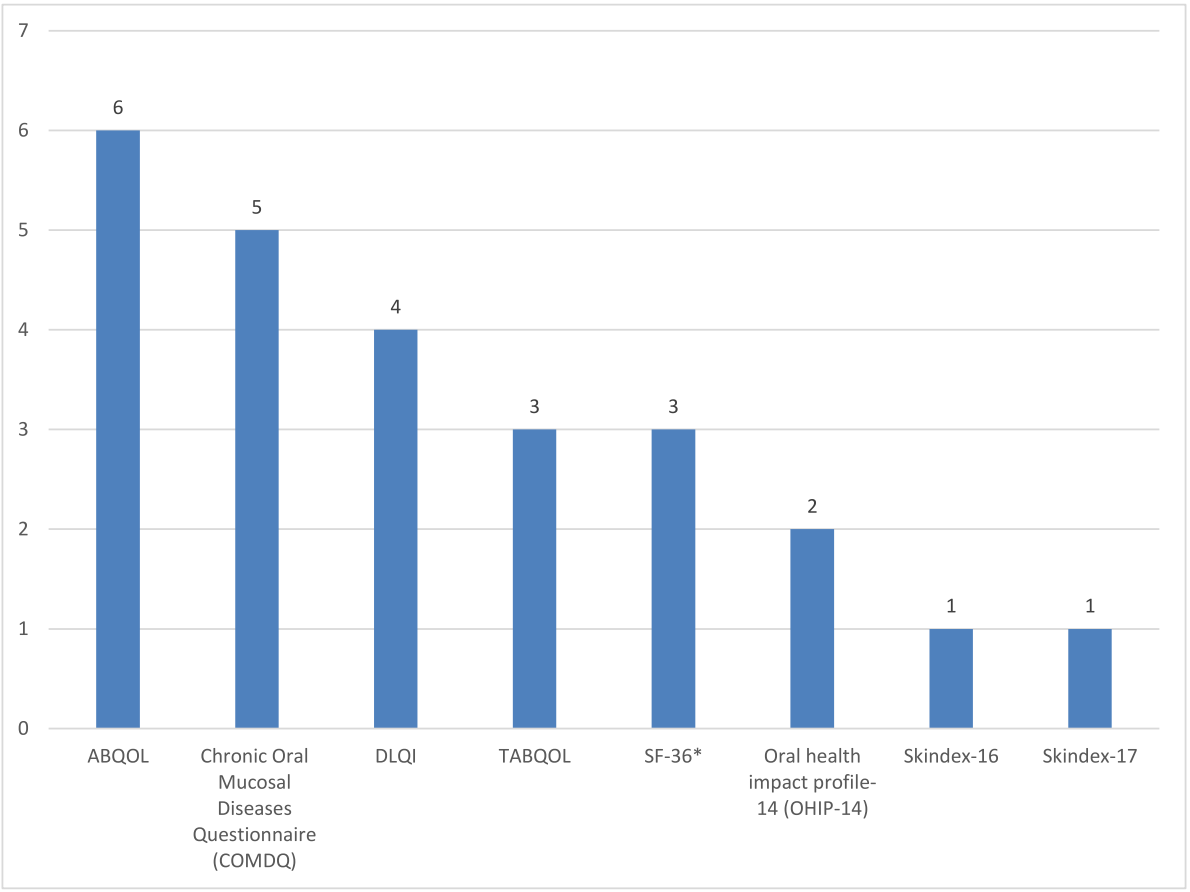

FIGURE 1 | The frequency of use of different health-related quality of life (HRQoL) instruments in the publications describing autoimmune bullous disease (AIBD) research. *In one study only the Mental Health subscale of the 36-Item Short Form Health Survey (SF-36) was used.

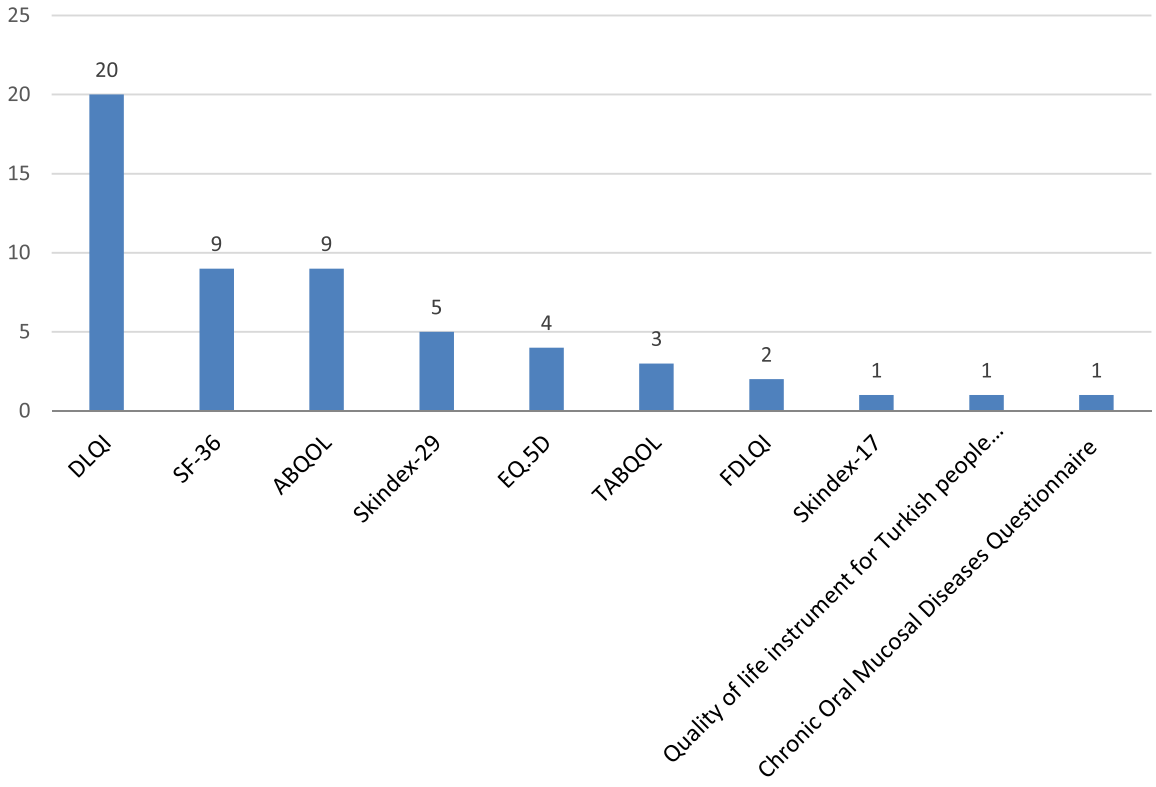

FIGURE 2 | The frequency of use of different health-related quality of life (HRQoL) instruments in the publications describing pemphigus vulgaris research.

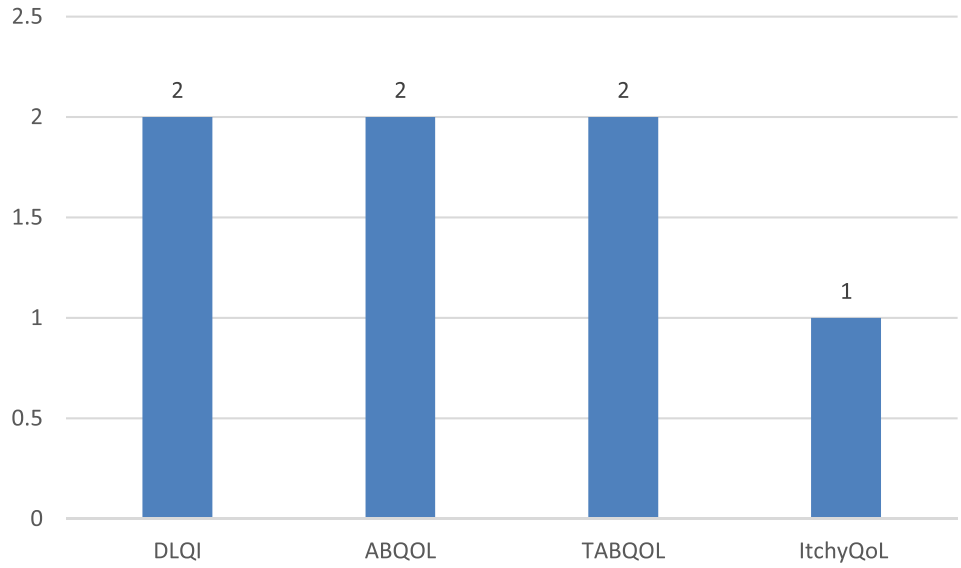

FIGURE 3 | The frequency of use of different health-related quality of life (HRQoL) instruments in the publications describing bullous pemphigoid research.

TABLE 1 | Autoimmune bullous disease (AIBD)-specific health-related quality of life (HRQoL) instruments.

Instruments	Structure	Scoring	Recall period	Validation
Autoimmune Bullous Disease Quality of Life (ABQOL) questionnaire [16]	17 items	For each question four optional answers exist and are scored from 0 to 3 points, yielding a total score from 0 to 51. Higher scores represent worse HRQoL	Last week	Convergent validity Discriminant validity Internal consistency Test–retest reliability
Treatment of Autoimmune Bullous Disease Quality of Life (TABQOL) questionnaire [17]	17 items	For each question four optional answers exist and are scored from 0 to 3 points, yielding a total score from 0 to 51. Higher scores represent worse HRQoL	Last week	Convergent validity Internal consistency Test–retest reliability

TABLE 2 | Oral health-specific health-related quality of life (HRQoL) instruments.

Instruments	Structure	Scoring	Recall period	Validation
Oral Health Impact Profile (OHIP)-14 [18]	14 items 7 domains: functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap	5-point Likert scale: never—0, hardly ever—1, occasionally—2, fairly often—3, very often—4 The OHIP-14 score can go from 0 to 56	Four weeks Alternative recall period of 7 days was also proposed [19]	Convergent validity Internal consistency Test–retest reliability Criterion validity
Chronic Oral Mucosal Diseases Questionnaire (COMDQ) [20, 21]	26 items 4 domains: pain and functional limitation, medication and treatment, social and emotional status, and patient support	5-point Likert scale: not at all—0, slightly—1, moderately—2, considerably—3, extremely—4 Total potential score from 0 to 104	Not stated	Convergent validity Discriminant validity Internal consistency Test–retest reliability Factor analysis

TABLE 3 | Dermatology Life Quality Index (DLQI) scores from different studies according to health-related quality of life (HRQoL) impairment severity descriptors.

Country	DLQI scores (mean ± SD)	Meaning of scores	References
Pemphigus			
India	27.8 (mean for two groups)	Extremely large effect on patient's life	[22]
Egypt	15.3 ± 4.8	Very large effect on patient's life	[23]
Iran	13.8		[24]
Turkey	11.6 ± 9.0		[25]
Iran	10.9 ± 6.9	Moderate effect on patient's life	[26]
Korea	10.2		[27]
Iran	10.1 ± 7.1		[28]
Germany	10 ± 6.7		[29]
International	9 (median)		[30]
Hungary	5.6 ± 7.0	Small effect on patient's life	[31]
Hungary	5.4 ± 6.8		[32]
Israel	4.6 ± 7.3		[33]
Netherlands	4.0		[34]
Malaysia	3.0 ± 8.0 (median)		[35]
China	3 (median)		[36]
Bullous pemphigoid			
Netherlands and Germany	11.3 ± 4.2	Very large effect on patient's life	[37]
Greece	9.5 ± 3.3	Moderate effect on patient's life	[38]

Face involvement and extent of lesions led to more severe QoL impairment measured by SF-36 [45]. The DLQI score was higher for patients with the mucocutaneous phenotype than for those with the mucosal phenotype [28].

The DLQI and ABQOL scores were not affected by gender, age, ethnicity, duration of illness [27, 35], subtype of pemphigus, or comorbidities [27]. In another study, women had a higher ABQoL total score in comparison to men [46].

Family Dermatology Life Quality Index (FDLQI) scores were significantly higher in older caregivers and married ones. There was a positive correlation between patients' admission frequency and FDLQI scores. The QoL of patients and their caregivers showed a significant positive correlation [28]. The DLQI [34, 37, 47–49], TABQOL [34, 37, 47, 50], ABQOL [49, 50], Skindex-29 [49, 51], OHIP-14 [15] and SF-36 [51] were used in clinical trials on AIBDs. ABQOL was also used for assessment of the efficacy of support group attendance [52].

The list of TFs' statements was formed, and all authors from both TFs voted for each of these statements (Table S2).

4 | Discussion

The ability to use a measure that has a validated system to interpret scores and has a known Minimal Clinical Important Difference (MCID), such as the DLQI, is an important aspect when choosing which HRQoL instrument to use [53]. The DLQI is the most widely used dermatology-specific HRQoL instrument in general [54, 55] and in AIBDs. In a prospective intervention study, the AIBD-specific ABQOL should be used at screening, baseline, and during follow-up. If there is a long-term maintenance phase, then measurement every 6 months, including the 12-month point, may be appropriate. The TABQOL should ideally be used at the same timepoints as the ABQOL. As TABQOL is a surrogate measurement of the impact of health interventions on QoL, it may be measured simultaneously with the Glucocorticoid Toxicity Index, which is measured at 3-monthly intervals [56, 57].

The oral disease-specific HRQoL instruments OHIP-14 and COMDQ were used in patients with oral involvement. Both instruments have shorter versions [58, 59] but these have to be validated in AIBDs.

The itch intensity of AIBD is correlated with expression of different itch mediators [60] and associated with a negative influence on HRQoL. Patients with a range of different chronic skin diseases are able to successfully self-assess the intensity of itch [61]. As expected, the majority of studies on AIBD showed significant correlations of HRQoL scores with disease severity measure scores [25, 27, 39–42]. The mean DLQI scores of patients with pemphigus revealed a wide range of HRQoL impairment across different studies [22–36]. However, these wide ranges of HRQoL impairment may be predominantly related to

the varying disease activity of subjects. Interpretation of data on gender differences is unclear where subjects are not appropriately matched for other characteristics [62]. The QoL of family members of patients with AIBD was also impaired, and scores correlated with those of the patient's HRQoL [28].

Fears related to COVID-19 may have influenced the reported HRQoL impact experienced by patients with AIBD. A large-scale population-based cohort study of 112 million individuals showed that COVID-19 infection is associated with an elevated risk for AIBD, while COVID-19 vaccination decreases the risk [63]. If possible, in people with COVID-19, standard long-term systemic treatment of AIBD should be continued similarly to recommendations for other skin diseases [64–66].

Bullying in patients with pemphigus vulgaris and bullous pemphigoid was reported in the EADV supported study on bullying in persons with skin diseases [67]. It is therefore important to consider measures to decrease stigmatization and bullying and to increase the availability of psychological support for such patients.

Most of the HRQoL instruments used in the studies reviewed were able to detect changes after treatment [34, 37, 47, 48]. In some clinical trials, the change in DLQI scores was greater than the DLQI minimal clinically important difference (MCID) [37, 48].

Further validation of some of the current HRQoL instruments designed for use in AIBDs is a task for future studies. In addition, a caveat of the two available AIBD-specific HRQoL instruments, ABQOL and TABQOL, is their validation for very different AIBDs such as pemphigus vulgaris, pemphigus foliaceus, bullous pemphigoid, and mucous membrane pemphigoid. These AIBDs are a heterogenous group of diseases with regard to age, itch, pain, mucous membrane involvement, dose, and length of immunosuppression, adverse events, comorbidities, and prognosis. Although in theory disease-specific instruments could be created for every skin disease, this would result in a vast and confusing array of measures, impractical for clinicians to use routinely [68]. When new instruments are created that are specific for individual AIBD, it is recommended that the development and validation be carried out across different countries to improve cross cultural equivalence [69–71].

There is more information on HRQoL assessment in skin diseases in other publications of the EADV TF on QoL and Patient Oriented Outcomes [66, 72–91].

5 | Conclusion

The EADV TFs encourage the use of the DLQI as a dermatology-specific instrument for HRQoL assessment in AIBDs.

The EADV TFs encourage the use of the ABQOL and TABQOL as AIBD-specific instruments for HRQoL assessment in AIBDs.

The EADV TFs encourage the use of the oral health-specific instruments OHIP-14 or COMDQ in AIBD patients with severe oral involvement. We do not recommend one of these instruments over the other. However, OHIP-14 has fewer items, and that may influence the choice for practical use.

The EADV TFs encourage the study, where appropriate, of family QoL of AIBD patients by using dermatology-specific family QoL instruments, such as the FDLQI or general measures such as FROM-16.

The EADV TFs recommend that HRQoL instruments be used in randomized controlled studies of new therapeutic approaches.

The EADV TFs encourage researchers and clinicians to validate and use HRQoL instruments in patients with AIBDs.

Conflicts of Interest

A.Y.F. receives a share of royalties for some use of the DLQI under standard university policy; honorarium from Lilly for the lecture in Tokyo, 2022 and honorarium from Tokyo Division of the Japanese Dermatology Association, 2022; travel expenses from meeting organizers to attend ISOQOL meeting, Calgary, Canada, 2023; travel expenses from International Psoriasis Council to attend IPC meeting Faroe Islands, 2023. D.F.M. had consulting fees, payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events from ArgenX, Sanofi Regeneron, Principia, Janssen, Lilly, Ono, Nurix, Almirall, RAPT, Roche; cocreator of PDAI, BPDAI, MMPDAI and Definitions; creator ABQOL, TABQOL; textbook: Blistering Diseases. F.P. had speaker's fees Skin Challenges 2023 from Abbvie; support for attending meetings and/or travel for Journées dermatologiques de Paris 2023 from Pfizer. F.S. had consulting fees from Abbvie. A.B. had royalties for Practical Psychodermatology (Wiley 2014); ad hoc consultancy fees from AbbVie, Almirall, BMS, Eli Lilly, Galderma, Incyte, Leo-Pharma, Janssen, Novartis, Pfizer, Sanofi, UCB; support for attending meetings and/or travel to BAD/EADV/AAD from Novartis, Galderma, UCB, Janssen, Sanofi; Immediate Past President of ESDaP; Medical Advisory Board of National Eczema Society, Ichthyosis Support Group and Psoriasis Association. E.A. had payments from Abbvie, LeoPharma, Lilly, Pfizer and Sanofi. J.C.S. had honoraria from AbbVie, LEO Pharma, Novartis, Pierre Fabre, Pfizer, Sanofi Genzyme, UCB, Sandoz, Almirall, Boehringer-Ingelheim, Janssen, Eli Lilly and Galderma; support in congress participation (registration fee, accommodation, transportation) from Novartis, UCB, Sanofi-Genzyme, Leo Pharma; President of the Polish Dermatological Society; Investigaror (not an employee relationship) for: AbbVie, Amgen, Bristol Myers Squibb, Galapagos, Galderma Incyte, InflaRX, Janssen, Kliniksa, Kymab Limited, Menlo Therapeutics, Merck, Novartis, Pfizer, Regereron Pharmaceuticals Inc., Trevi Therapeutics, UCB Pharma, Almirall, Amgen, AnaptysBio, Boehringer Ingelheim, Celtrion, Helm AG, Leo Pharma, Medimmune, Teva, Ventyx Bioscience, Uni Therapeutics, CuraTeQ Biologics, BioThera, ASLAN, Biocom, Biogen, Argenx, DICE Therapuetics, Aceleryn, Moonlake and Takeda. V.P.W. had payments from Janssen, CSL Behring, Argenx, Regeneron, Sanofi, Calyx, Cabaletta Bio, Anaptysbio. Grant funding from Regeneron, CSL Behring. University of Pennsylvania owns the copyright (no-cost) for the PDAI and BPDAI. E.S. had institutional grants from Fresenius Medical Care, Novartis, Incyte, Biotest, ArgenX, Dompe, Admirx, CSL, AstraZeneca, Bayer, Pharmaxis, Alpine Immune, Euroimmun and Sanofi; consulting fees from Bristol-Myers Squibb, ArgenX, Janssen, Sanofi, Ono and AstraZeneca; payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events from Sanofi, Almirall and Fresenius Medical Care; support for attending meetings and/or travel from Sanofi, Almirall, Chugai, Fresenius Medical Care, Bristol-Myers Squibb; institutional patents planned, issued or pending for Dompe and Euroimmun; participation on a Data Safety Monitoring Board or Advisory Board of ArgenX and Sanofi. Other authors reported no conflicts of interest.

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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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Appendix A

Multiple Choice Questions

1. The DLQI has a validated score meaning banding system
   a. True
   b. False
2. Family QoL of patients with AIBD is often impaired
   a. Yes
   b. No
3. The ABQOL and TABQOL are AIBD-specific instruments
   a. True
   b. False
4. OHIP-14 and COMDQ can be used in AIBD patients without oral involvement
   a. Yes
   b. No
5. The EADV TFs recommend that HRQoL instruments be used in randomized controlled studies of new therapeutic approaches
   a. True
   b. False