Quality of Life Measurement in Atopic Dermatitis. Position Paper of the European Academy of Dermatology and Venereology (EADV) Task Force on Quality of Life

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Conflict of interest

AYF is joint copyright owner of the DLQI, CDLQI, IDQoL, DFI and FDLQI

Abstract

There is a need for researchers to have easy reference to the wide spectrum of different types of quality of life (QoL) instruments that can be used in atopic dermatitis (AD). Previous reviews on QoL in AD do not cover the full spectrum of QoL measures used in studies on AD. This paper, on behalf of the European Academy of Dermatology and Venereology (EADV) Task Force on QoL contains information on instruments available for health-related QoL and family QoL assessment in AD including information on validation, experience of QoL assessment in AD for different purposes, peculiarities of QoL assessment in different age groups, expert analysis of available instruments including data on limitations of their use and recommendations of the Task Force.

Introduction

There is a need for researchers to have easy reference to the wide spectrum of different types of quality of life (QoL) instruments that can be used in atopic dermatitis (AD). Previous reviews on QoL in AD do not cover the full spectrum of QoL measures used in studies on AD.[1] A recent review on QoL instruments in adult AD[2] did not identify a specific QoL instrument to be recommended for use in adult AD patients. This paper, on behalf of the European Academy of Dermatology and Venereology (EADV) Task Force (TF) on QoL contains information on instruments available for health-related (HR) QoL and family QoL assessment in AD including information on validation, experience of QoL assessment in AD for different purposes, peculiarities of QoL assessment in different age groups, expert analysis of available instruments including data on limitations of their use and recommendations of the Task Force. Although we do not attempt to define the "best" QoL instrument, the information provided should help dermatologists and researchers to choose appropriate QoL instruments and avoid common mistakes.

Methods

Members of the European Task Force on Atopic Dermatitis were invited to participate and Prof. Oranje agreed to join the working group. The literature search was performed using the PubMed database, which was searched from 1990 to November 2015 using the key word combinations: "Atopic dermatitis, quality of life" and "Atopic eczema, quality of life". All publications written in English or that had English abstracts were considered. Duplicated and unrelated references and review articles were excluded. The remaining sources were analyzed and a list of QoL instruments that were used in AD was formed. Additional searches for "Name of measure" and "Atopic dermatitis/eczema" for each of the measures from this list was done. The results are presented in three sections: instruments for HRQoL and family QoL assessment in AD;

peculiarities of QoL assessment in different age groups of patients with AD; reasons why QoL assessment may be useful in AD.

Results

HRQoL and family QoL instruments in AD

A list of generic, dermatology-specific and AD-specific instruments with brief descriptions and information on validation are presented in Tables 1-3. In several publications[42,43] the names of the QoL instruments used are not given. In some other studies unvalidated "study-specific" instruments were used, some brief and simple[44-47] and others more complicated.[48-52] A "modified" DLQI was used in one study to measure the impairment of "itch-related" QoL.[53] Some QoL instruments with non-English original versions are given alternative titles in different publications. For example, Fragebogen Alltagsleben (FAL), ALLTAG and "Daily life" are alternative titles of the same German instrument.[16]

QoL assessment in different age groups of patients with AD

We did not find information concerning specific aspects of HRQoL that may be affected differently in different age groups of adults with AD. There are several AD-specific HRQoL instruments created especially for children. Most studies on QoL in young AD patients used the Infants Dermatitis Quality of Life Index (IDQoL)[31]. However, other AD-specific proxy-instruments, the Childhood Atopic Dermatitis Impact Scale (CADIS) encompassing mixed proxy and family QoL[37] and the Childhood Impact of Atopic Dermatitis (CIAD)[40] were also used. The most widely used instrument for self-assessment of HRQoL in children with AD is the dermatology-specific Children's Dermatology Life Quality Index (CDLQI).[18] Several generic instruments have also been used to assess QoL of AD children: these include Fragebogen für KINDer und Jugendlichezur Erfassung der gesundheitsbezogenen Lebensqualität (KINDL)[6], Quality of Life Scale for Children (AUQEI)[7], DISABKIDS Chronic Generic Measure (DCGM-37)[10], Pediatric Quality of Life Inventory (PedsQL)[15], Vécu et Santé Perçue de l'Adolescent

(VSP-A) [14], Children's Quality of Life Index (CLQI)[17], FAL/ALLTAG[16] and AD-specific DISABKIDS AD Module (ADM)[36]. Because the lives of children alter greatly between the ages of 4 and 16 years, in the consideration of HRQoL children are not a homogenous group. Jirakova et al.[54] divided children into two age groups, 7-13 years and 14-18 years, and found significant differences in two CDLQI items: problems in playing and doing hobbies and problems during school or holidays.

Several AD-specific family QoL instruments have been created to try to measure the secondary impact of having someone in the family with AD on the QoL of other family members. These include the Dermatitis Family Impact (DFI)[34], Quality of life in Primary Caregivers of Children with AD (QPCAD)[35], Parents' Index Quality of Life-AD (PIQoL-AD)[38], The Quality of Life in Parents of Children with AD[39] and CADIS (mixed proxy and family QoL instrument).[37] The dermatology-specific Family Dermatology Life Quality Index (FDLQI) was created to measure the impact in family members of patients with all skin diseases and from all age groups.[19] The FDLQI may be as effectively used by parents of children with AD as it can be used by family members of adult dermatology patients.[55]

Use of Qol Measures in unvalidated or inappropriate age groups

An important issue is the quite frequently reported use of HRQoL instruments out of their validated age limits. For example Skindex-29, an instrument for adults, was used in children from 13 years old[56] and the DLQI, designed for use in those over 16 years old, was used in children from 8 years old.[57] The CDLQI, originally validated for use in children from 4 to 16 years old, was used in children aged 3 years[58], 2 years[59-62] and even 1 year of age.[63,64] The IDQoL has been used in children under 6[54] and 7 years of age[65], though it is only meant to be used in infants. Using this measure in older children was explained as being necessary because of the education system in the Czech Republic.[54] The IDQOL is recommended to be used by children aged from newborn to 3 years of age and CDLQI by children from 4 to 16 years of age.

The lower age cutoff was chosen because of the way in which a four year old behaves and the relevance of the questions to this age group. Although reasons were given[54] why in a study in the Czech Republic different age limits were applied for the use of the IDQoL and CDLQI, the original validated age recommendations remain those recommended by the authors. The scores of 33 teenagers with AD were presented as part of the data used for validation of the dermatology-specific Skindex-teen questionnaire.[66] The generic HRQoL instrument for adolescents, VSP-A, was used in French children during the validation of the DISABKIDS instrument.[10] The dermatology-specific CDLQI questionnaire[67] has been used to study the specific problems experienced by adolescents.

Reasons for assessment of QoL in AD

Clinical trials

Several different QoL instruments have been used in clinical trials of AD as outcome measures (Table 4). The DLQI and CDLQI have been the most frequently used, and the IDQoL and DFI are the most widely used AD-specific and infant and family QoL instruments. In some clinical trials "study-specific" non-validated instruments were used.[45,49,47,119] Reports of other trials do not contain information on which HRQoL instruments were used.[42,120]

Impairment of HRQoL and family QoL

Several questionnaires were used simultaneously in studies of how QoL is impacted in AD patients and their families (Table 4).

Creation and validation of instruments

Several publications describe the creation and validation of QoL instruments, and their culturally validated local versions, in AD patients and in parents/caregivers (Table 4). The DLQI, DFI and PIQoL-AD have also been used in the validation process of non-QoL instruments.[121-123]

Correlation of QoL and AD severity

Many authors have presented data on the correlation of QoL and AD severity as a secondary outcome, but in addition there are several studies primarily aiming to study this correlation. Correlations have been reported between the generic measure Short Form Health Survey (SF-36), dermatology-specific measures DLQI, CDLQI, Skindex-29, AD-specific measures IDQoL, the family QoL measure DFI, the German questionnaire "Quality of life in parents of children with atopic dermatitis", and PIQoL-AD, along with scoring of AD (SCORAD), patient oriented (PO)-SCORAD, Eczema Area and Severity Index (EASI) and other AD severity scales.[123-131] There have been significant positive correlations between DLQI, IDQOL, DFI with SCORAD[125-126], and some studies not finding such correlation.[128,132] DLQI, DFI, IDQoL and CDLQI were well correlated with PO-SCORAD, suggesting the importance of the patient's perspective.[129-130] Self-assessed HRQoL of children with AD correlated better with disease severity than family QoL results[133]. HRQoL measured by the DLQI, Skindex-29 and PIQoL-AD did not correlate with the severity of AD measured by the EASI.[123-124]

Educational programs

The QoL instruments that have been used to assess the efficacy of different educational programs are given in Table 4. The impact of support groups on HRQoL has been measured using the CDLQI, improving personal relationships and leisure time.[103] DFI scores suggested that involvement with support groups[103] or undertaking a two day parental education programme[134] is not enough to improve family QoL. However the importance of intensive educational programmes in children (5-16 years old) was confirmed by an improvement of the IDQOL, CDLQI and DFI scores.[135] Web-based education programs had a beneficial effect on the HRQoL of AD children, as measured by the IDQoL.[136] Parental counseling sessions about medical, nutritional and psychological issues improved treatment habits, costs and coping strategies in a study using the FAL/ALLTAG questionnaire.[107] Another German questionnaire "QoL in parents of children with atopic dermatitis" was used to analyze the impact of longer educational programmes for parents of AD children and teenagers. There were better results in

children less than 7 years old.[137] The same measure was used to show that child-parent interventions could change the psychological parameters that could influence adherence and the success of therapy, by improving their coping strategies for control of scratching.[105] Six weekly meetings as part of a multidisciplinary approach involving a pediatric allergist, dermatologist and psychologist had a significant improvement on IDQOL and DFI scores, also decreasing the levels of parents' anxiety.[104] DLQI and CDLQI scores have revealed the impact of daily text messages for six weeks as medication reminders and education for teens and adults.[138] The on-line self-management programme "Living with eczema" improves DLQI scores.[139] DLQI and SCORAD scores were significantly improved by referral of atopic adults to secondary care, probably due to decreasing worries and concerns regarding their disease.[140]

Impact of AD and other diseases

Generic and dermatology-specific HRQoL instruments that have been used to compare the impact of AD and other diseases are given in Table 4. These studies confirmed that AD has a high impact on social functioning and psychological well-being, similar to other chronic dermatological conditions (psoriasis, Darier's disease and Hailey-Hailey disease), hypertension, depression and type II diabetes.[141] The use of the DLQI, Skindex-29 and the EQ-5D in large population studies showed lower QoL in people with self-reported skin diseases (including AD) than in the general population.[108] Chronic diseases such as AD had a higher impact on QoL, as measured by the CDLQI and AUQEI, than molluscum contagiosum.[117] In children, AD and psoriasis result in the highest CDLQI scores, followed by urticaria and acne.[17] Vitiligo may cause greater impairment of HRQoL, assessed by the CDLQI, than AD.[109] Generalized AD resulted in greater impairment of QoL than severe systemic diseases such as cystic fibrosis, asthma, epilepsy or diabetes.[17] Skindex-29 scored more highly in AD than in "intrinsic AD".[56] Use of the KINDL-R showed that acute AD and hay fever could have a higher impact on QoL than asthma.[113] Young, single, poor patients with a long-duration of AD, psoriasis, vitiligo and acne report a lower QoL.[142] Use of the generic measure, SF-12, has shown that psoriasis patients

may experience a greater impact on their QoL and higher perceived stress than AD patients.[112] Using the DLQI and Skindex-16 it was shown that psoriasis has a higher effect on desire to be with people, showing affection and causing more problems with the treatment, whereas in AD itching causes higher negative impact on QoL. Psoriatic patients with only mild disease may experience a large negative effect on their QoL, a scenario not typical for AD patients.[110] A study using the Adjustment to Chronic Skin Diseases Questionnaire (ACSD) suggested that the impact of psoriasis is greater than that of AD.[118] Another study showed that only arthropathic psoriasis had a higher impact on HRQoL than AD, as measured by the SF-36 and the DLQI.[143] DLQI measurement showed that in both psoriasis and AD, hospitalization could have a positive effect on QoL.[144] The willingness to pay in both AD and psoriasis correlates with DLQI scores.[145] DLQI scores are better correlated with measures of depression, anxiety and personal interactions in AD than in vitiligo or healthy controls.[146]

Other reasons to assess QoL in AD

Other studies where QoL of AD patients and/or their families was studied are given in Table 5.

Discussion

The use of a wide range of QoL instruments has confirmed the impairment of QoL experienced by AD patients and their family members. Despite there being a range of reported correlations between HRQoL instruments and AD severity measures[128,129], it is clear that HRQoL is generally more impaired in patients who have a more severe clinical course of AD.

Generic instruments should be used to compare QoL impairment in AD with non-dermatologic conditions: dermatology-specific instruments may be used to compare QoL across different skin diseases. However, Twiss and McKenna[176] used two disease-specific instruments that were created on the same principles (PSORIQoL and QoLIAD) to compare QoL impairment in AD and psoriasis. Dermatology-specific and disease-specific questionnaires may have a greater capacity for differentiation and be more sensitive to change than generic measures. Using a

questionnaire which is not specifically tailored to the disease could mean that some issues associated with the disease are not recorded.[177] When the generic SF-36 was used in AD, there were only small score differences between patients with mild and moderate eczema and between mild eczema and healthy controls, and no significant correlation with AD severity, in contrast with reported correlations using the dermatology-specific DLQI and CDLQI.[178]

There are many types of validated HRQoL instruments. Questionnaires should be tested for scale structure, reliability, validity and responsiveness. Additional validation methods are used to assess the quality of instruments. However some researchers have used "study-specific" instruments without any validation. Such practice negates the scientific value of the published results and may discredit HRQoL assessment. It is impossible to rely on the results of studies when authors do not mention the name of the QoL instrument used: authors should always give the names of any QoL instruments used in reported studies. Where a single instrument has more than one descriptive title, the original title should be given, along with the original reference to its publication, in order to avoid confusion. Editors should ensure that published QoL data at least meets these minimum requirements. The use of modified versions of validated instruments is often described. However, such adapted questionnaires should be fully revalidated.
As the QoL impacts experienced by people aged 16-17 may differ from those experienced by children or adults, QoL measures designed for use in this age range may have advantages over both child- and adult-specific measures.[179] Though AD is relatively uncommon in the elderly, the numbers of elderly patients with AD are gradually increasing in industrialized countries, associated with an aging society.[180] There may be specific ways in which elderly people are affected by AD that result in specific needs: prospective research is required to address this.

It is possible to capture, with parental assistance, self assessment of QoL in children as young as four years old, with the help of illustrated questionnaires. In younger children outsider or proxy ratings can be used, but this brings with it the potential problem of adult-child concordance.[181,182]

Because of possible discrepancy between self and proxy reports we recommend that proxy-rating questionnaires should only be used as a single measure in the youngest age group and in those patients who are unable to self-assess. Spouses can report differing views, not associated with gender.[183] Therefore it would seem better to involve both parents in completing proxy rated questionnaires, though this may be impractical. Cartoon versions of the questionnaires are preferable, especially for the youngest patients.

Questionnaires should be selected that are appropriate for the ages of the subjects studied. If instruments have to be used out of their validated age limits, they should be revalidated. Some reports have combined scores of the DLQI and CDLQI: such combination is inappropriate[184] as these instruments have different questions specific to the age groups for which the questionnaires are designed. The validated score banding descriptors, for example, are different.

The selection of an appropriate HRQoL instrument in clinical research or practice depends on the research question and the target population in which the HRQoL instrument is administered.[185] We recommend the use of validated AD-specific instruments in addition to generic and dermatology-specific questionnaires. The use of novel instruments with limited validation and lack of validated translations may meet the needs of a local study, but such use will inevitably limit comparability and interpretation of the results in a wider context. Because of the significant family impact of AD we recommend that family QoL should be further studied, especially concerning young children. This may help to improve clinical consultations and choice of appropriate treatment strategy.

This publication has focused on the large numbers of published research studies using QoL measures in AD. However there is virtually no information about the routine use of QoL measures in the routine management of such patients, a question that is arguably of greater practical importance to clinicians. If physicians choose to use a QoL measure in clinical

practice, then issues such as simplicity of use and ability to interpret scores become of great importance.

Limitations

Because of space limitations and the high number of articles on QoL in AD, the number of references identified and reported per instrument in this paper may not reflect the actual frequency of the use of that instrument.

Conclusion

The summarized recommendations of the Task Force are presented in Table 6 and Figures 1 and 2. This paper should help dermatologists and researchers to choose appropriate QoL instruments for their needs and avoid common mistakes.

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