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Measuring the impact of dermatological conditions on family and caregivers: a review of dermatology-specific instruments

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Conflict of interest

AYF is joint copyright owner of the DFI, FDLQI, PFI-14 and FROM-16 and member of an advisory board for Novartis. SS is joint copyright holder of FROM-16.

Abstract

The patient is the centre of a web of relationships and the impact of his/her disease on family members and caregivers must be taken into account. The aim of this study was to identify the specific instruments that measure the impact of a dermatological disease on the quality of life (QoL) of family members, by performing a systematic search of the literature. Fifteen papers were identified, describing the creation and validation of nine instruments. Four of them concerned atopic dermatitis (Dermatitis Family Index, DFI; Parents' Index QoL Atopic Dermatitis, PiQoL-AD; QoL in Primary Caregivers of children with Atopic Dermatitis, QPCAD; Childhood Atopic Dermatitis Impact Scale, CADIS), two measured the impact of psoriasis in family members (Psoriasis Family Index, PFI; FamilyPso), one the impact of epidermolysis bullosa (Epidermolysis Bullosa Burden of Disease, EB-BoD), one of ichthyosis (Family Burden Ichthyosis, FBI), and one was generic for dermatological conditions (Family Dermatology Life Quality Index, FDLQI). The EADV quality of life taskforce recommends that the impact of a skin disease on family and caregivers should be measured as part of any thorough evaluation of the burden of a disease. Guidelines are given to choose the most appropriate instruments.

Introduction

Skin conditions may have an impact not only on the patient's life, but also on the lives of family members and caregivers ¹. Basra and Finlay proposed the concept of 'the Greater Patient' ^{2,3} to describe the group of people who are close to a patient, and whose lives are therefore also affected by the patient's disease. The patient is at the centre of a web of relationships, which have to be taken into account when planning care. This is particularly true when the patient is a child, for example with atopic dermatitis ^{4,5}, where family members are burdened with time-consuming treatment regimens and dietary and household changes, as well as financial impact. However, the family members of adult patients with chronic skin disease may also experience practical and psychosocial consequences. Finlay ⁶ defined three dimensions of skin disease burden: 'now', 'long term' and 'family', the first two concerning the patient, while the third dimension is the burden on the partner, family members and caregivers. In the last decade, there has been growing interest in this 'third dimension', however, the physical, psychosocial and economic impact of skin conditions on informal caregivers is still often unrecognised or underestimated. Only a few specific instruments have been created to measure this impact.

The aim of this study was to identify and describe the instruments that measure the impact of a patient having a skin disease on the quality of life (QoL) of family members, by systematically searching the literature. On behalf of the European Academy of Dermatology and Venereology (EADV) Taskforce on Quality of Life, we evaluated these instruments using standard criteria, in order to provide guidelines for their use.

Materials & methods

A systematic search of the literature was undertaken to identify current instruments for assessing QoL in families and caregivers of patients with skin conditions.

Data source and search terms

The MEDLINE database (using PubMed) was searched. The review covered the time period up to December 31st, 2016. The following structured search terms were developed using PubMed guidelines and MESH terms and were used in the database search: (dermatol* OR skin) AND (quality of life OR life quality) AND (caregiver OR carer OR family OR familial OR parent OR partner OR proxy).

Selection procedure

The titles and abstracts resulting from this search were screened for relevance. The full text articles were obtained for all titles/abstracts that appeared to meet the inclusion/exclusion criteria or where there was any uncertainty. The full text articles were then screened.

The references given in the included articles were checked to identify other relevant articles. We only selected articles describing instruments that were designed specifically for dermatological conditions.

Selection criteria

The following articles were included: 1) articles that identified a technique (tool, instrument or questionnaire) for evaluating QoL and family reported outcomes in families, partners or caregiver of patients with skin disease; 2) articles that assessed the performance of these QoL instruments; 3) articles in the English language.

The following articles were excluded: 1) articles related to general (not specific for dermatology) QoL measures designed to assess QoL of family, partner, caregiver or carer of patients; 2) articles describing only the use of specific measures designed to assess QoL of

family, partner, caregiver or carer of patients with skin conditions; 3) reviews on the topic; 4) articles describing instruments for which an English translation is not available.

Evaluation criteria

Instruments were analysed according to the criteria used by Both et al. ⁷ (Table 1). A score is given to the different properties that a measurement instrument should have, i.e., validity, interpretability, reliability, structure, responsiveness, item bias, cultural issues, respondent and administrative burden, and alternative forms. Each instrument was independently assessed by two authors (a different combination of authors for each instrument) and reviewed by FS.

Discrepancies were discussed until an agreement was reached.

Check of search completeness

Any published new measure for family impact of skin disease will likely cite articles describing previous methods of measurement. Therefore articles that cited the original descriptions of the DFI, CDLQI, CADIS, PIQoL, QPCAD and PFI were identified on Google Scholar and checked to ensure that no other dermatology-specific measurement methods had been missed.

Results

The first PubMed search (December 2016) identified 862 papers. From these, we selected 60 papers, by reviewing each title and abstract (see flowchart, Figure 1). Seven of the papers described general concepts, such as the impact of disease on family members ^{1,8}, the Greater Patient concept ^{2,3}, the three dimensions of skin disease burden (now, long term, and family)⁶, and the impact of atopic eczema on the family ^{4,5}.

Some articles concerned the measurement of the impact of a skin disease on family members, but did not use an instrument specifically designed for that purpose. For example, Misery et

al.⁹ in a study of relatives of patients with atopic dermatitis used the SF-12, the short version of the SF-36, which is a generic instrument used as a population health measure, and the Epworth scale, a self-assessment questionnaire consisting of eight items which evaluate daytime sleepiness. In a study on the impact of haemangiomas in children on their parents¹⁰ a series of single questions were used but not a structured questionnaire. The Hamilton Anxiety Scale and the Beck Depression Inventory have been used to assess depression and anxiety in the caregivers of pediatric dermatological patients¹¹. Family dynamics have been specifically studied in a study of children with atopic dermatitis¹², using the family APGAR instrument. To describe the impact of cutaneous T-cell lymphoma on family members and how they cope and adjust, Selman et al.¹³ conducted semi-structured qualitative interviews and data were analysed thematically using the Family Adjustment and Adaptation Response model as an interpretative framework. Another study was excluded because although the QoL instrument was completed by parents, it actually evaluated the QoL of the child (PedQL-P¹⁴: Pediatric Quality of Life Inventory Parent Versions). All six of these articles were excluded from further analysis for the reasons given above.

Among the 47 remaining papers identified concerning use of dermatological QoL instruments in family and caregivers, one was a review of an instrument, 25 concerned the use of instruments, six described the validation of instruments in different languages, and two described instruments in languages other than English. Two more articles were included from a further search using the names of identified instruments, giving a total of 15 papers included in the review.

From these papers, nine measures were identified, described in detail below. The analysis of these instruments, based on the criteria in Table 1, is given in Table 2. The main characteristics of the instruments are described in Table 3.

Of the 862 articles identified, 70 were in languages other than English: French 20 articles, German 14, Spanish 10 and articles in thirteen other languages. We have reviewed the titles and, where relevant, abstracts of these articles. No measurement instrument was described or used in these articles that had not already been identified from the English language publications. As a further check that no measures had been missed, articles identified by Google Scholar, that cited the original descriptions of the DFI (330 citations), CDLQI (93), CADIS (81), PIQoL-AD (77), QPCAD (20) and PFI (15) were reviewed. No additional dermatology specific measurement methods were identified from this review.

Family Dermatology Life Quality Index (FDLQI)

The FDLQI^{15,16} is a dermatology-specific instrument which measures the adverse impact on the health-related QoL of family members of patients with skin disease. The questionnaire was based on information from semi-structured interviews with family members or partners of patients with a variety of skin diseases. A draft questionnaire of 19 items was created, which was tested for face and content validity, and 10 final items were selected. Italian¹⁷, Persian¹⁸ and Ukrainian¹⁹ versions have been published. Other articles have described the use of the FDLQI²⁰⁻²⁵.

Dermatitis Family Index (DFI)

The DFI questionnaire^{26,27} is a disease-specific measure to assess the impact of atopic eczema on the QoL of the parents and other family members of affected children. An Arabic version²⁸ and a Ukrainian version²⁹ have been published. The DFI has been used in many studies³⁰⁻⁴⁵. A review of the use of the instrument⁴⁶ showed that 26 studies correlated the DFI to other instruments, demonstrating its convergent validity. Internal consistency was demonstrated by three studies, with Cronbach's alpha ranging from 0.85 to 0.90, and test-retest reliability by

one study. Fifteen studies demonstrated that DFI scores change in response to changes in the clinical condition of the affected child, thus confirming sensitivity to change. The DFI has been translated from English into 17 languages. Some studies used modified versions of the DFI ⁴⁷⁻⁴⁹.

The Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD)

The PIQoL-AD ^{50,51} aims to give information on the impact, caused by childhood atopic dermatitis, on the QoL of the caregiver of affected children, aged 8 years or younger. The instrument was developed in several different countries simultaneously, starting from qualitative interviews. Rasch analysis was applied and items were removed from the initial 45-item draft of the instrument in order to minimise misfit and redundancy and to ensure the unidimensionality of the scale. A final version of 28 items was obtained. A change of 2 to 3 PIQoL-AD points over time could be considered meaningful. The instrument has only been used in a few studies ^{52,53}.

Measure of quality of life in primary caregivers of children with atopic dermatitis (QPCAD)

The QPCAD ⁵⁴ is a self-report questionnaire to evaluate the QoL in the past week of primary caregivers of a child with atopic dermatitis. The preliminary QPCAD was created using semi-structured interviews and consisted of 85 items grouped into 7 domains. The number of items was reduced to 19 on the basis of their meaning, then to address the floor effect, and finally using factor analysis. This instrument has only been used in the Japanese version. A short version is available ⁵⁵.

Childhood Atopic Dermatitis Impact Scale (CADIS)

The CADIS ^{56,57} measures the effects of atopic dermatitis on the QoL of affected children younger than six years and their families. A prototype 62-item instrument was developed from a conceptual framework based on data from a literature review and from directed focus sessions with experts and parents. Item reduction was performed using Rasch analysis and a shorter 45-item version obtained. The CADIS is responsive to clinical changes in atopic dermatitis, and correlates well with the SCORAD score.

Psoriasis Family Index (PFI)

The PFI ⁵⁸⁻⁶⁰ is a disease-specific instrument to measure the secondary impact of psoriasis on the health-related QoL of family members of psoriasis patients. The questions were based on information from interviews with relatives of people with psoriasis. Following description of the first 15-item version, psychometric properties of the PFI were assessed using the Item Response Theory Rasch model, which suggested that no changes were required to the measure apart from the removal of one item. The final version consists of 14 questions. A Brazilian Portuguese version has been validated ⁶¹.

FamilyPso

The FamilyPso ⁶² is a questionnaire measuring the impact of psoriasis on partners or family. It was developed on the basis of a literature research and qualitative interviews with family members. It is possible to calculate a total score, which has high reliability. It has good convergent validity, being strongly correlated to the FDLQI ($r=0.77$). In comparison with the PFI-14, the FamilyPso has a greater focus on the emotional aspects of living with affected family members.

Epidermolysis Bullosa Burden of Disease (EB-BoD)

The EB-BoD is a disease specific questionnaire assessing the burden on families of children with epidermolysis bullosa (EB) ⁶³. It consists of 20 items. The questionnaire showed high internal consistency, with Cronbach's alpha=0.90, and the intraclass correlation coefficient was 0.97. The EB-BoD score correlated with the mental scale of the SF-12, showing convergent validity, and EB-BoD was able to discriminate among the different clinical subtypes of EB. Sensitivity to change was not tested.

Family Burden Ichthyosis (FBI)

The FBI ⁶⁴ is a questionnaire designed to specifically measure the burden on families of patients affected by ichthyosis. It correlates with the mental scale of the SF-12, showing convergent validity. The five dimensions of the FBI were significantly correlated with the severity score. The questionnaire was created in French and translated into English according to good practice, including cross-cultural validation.

Other questionnaires

A 22-item German questionnaire for parents of children with atopic eczema (Fragebogen für Eltern von Neurodermitis kranken Kindern; FEN) has been developed ⁶⁵ and used ⁶⁶. The FEN includes four subscales: "aggressive behaviours towards scratching" (8 items), "protective behaviour" (7 items), "control of scratching" (4 items), and "negative experiences with the treatment" (3 items). High total scores represent high parental strain resulting from atopic dermatitis.

"Fragebogen zur Lebensqualität von Eltern neurodermitiskranker Kinder" (Quality of life in parents of children with atopic dermatitis) ⁶⁷, is another German instrument, used by von Räden et al ⁶⁸ and used in another study, with the name of "QoL in Parents of Children with Atopic Dermatitis" (PQoL-AD) ⁶⁹. It consists of 26 items, which can be divided by

factor analysis into five interpretable subscales: psychosomatic well-being, effects on social life, confidence in medical treatment, emotional coping, and acceptance of the disease. Convergent validity has been tested. The questionnaire is able to highlight differences between parents of children with varying degrees of disease severity, which is a prime indicator of clinical relevance. The questionnaire has shown high intraclass coefficients for test-retest reliability. The reliability of the subscales was medium to high, based on a Cronbach's alpha of between 0.57 and 0.90. The intercorrelations of the dimensions are moderate (0.20-0.63), which suggests that each dimension gives independent information on the various aspects of QoL.

Discussion

There is an increasing interest in the impact of skin conditions on family members and caregivers of patients. New instruments have been created to assess this often hidden aspect of the burden of skin disease. On reviewing the literature to identify the measurement instruments that are currently available, we found nine main instruments. Four of these were designed for use in atopic dermatitis. As this disease generally affects children, who need to be taken care of, the burden that atopic dermatitis has on caregivers was an obvious first area on which research was focussed. The first questionnaire on family burden was the DFI, which has since become the most used and most widely translated. Over the same period, two German questionnaires (FEN and PQoL-AD) were created, then the PiQoL-AD, followed by the QPCAD and the CADIS. These last instruments have been used in very few studies. In general, the validity and reliability of the instruments concerning atopic dermatitis have been appropriately addressed, however some of their properties still need to be evaluated. In particular no information been published concerning interpretation of scores for any of these instruments, for example score banding descriptors or minimal clinically important score

difference to aid interpretability of score change. Such information is particularly important to make measures useful clinically by giving meaning to scores and to their change over time. Rasch analysis, for item selection and to test unidimensionality, was performed in the development of three measures, the PiQoL-AD, the CADIS, and the PFI-14: in the development of the other questionnaires items were selected by factor analysis. Cultural aspects were generally not addressed, though they should be considered, especially since the instruments were created in and used in different countries. For example the QPCAD was created in Japan, and the authors emphasized ⁵⁴ that some cultural differences are present compared to instruments such as the DFI. Items related to financial demands and leisure were excluded from the final version of the QPCAD, since in Japan it is taken for granted that parents will make sacrifices for their children, and medical expenses are covered by national health insurance. As a further reassurance that this review has not missed any relevant dermatology-specific measurement methods, two systematic reviews did not identify any other methods. ^{39,70}

Although the concept of “family” is apparently self-evident, in reality it is difficult to define and the concept differs between different cultures and has also been changing with time ¹. The measures identified in this study were all designed to measure the impact “of having someone in the family with a skin condition” on specific individuals. None of the measures were designed to assess the overall burden on the family unit (the total Greater Patient), though the names of the measures may be wrongly interpreted as suggesting this. There is also a difference in the meaning of “caregiver” and “family member”: a family member might or might not also be a caregiver, and a caregiver might or might not also be a family member. Even though a sick child necessarily involves the lives of people close to the child, the concept of the Greater Patient ^{2,3} can be applied to all patients, since every human being is the centre of a web of relationships. Based on this assumption, Finlay et al. created the FDLQI, an

instrument which measures the adverse impact on the health-related QoL of family members of patients with any skin disease. The advantage of a dermatology-specific instrument is that it may be used in all dermatological conditions, and it allows comparisons among skin diseases, though to compare the impact on family members of a skin disease with a non-skin disease a generic measure that can be used across all of medicine, such as FROM-16⁷¹, would need to be used.

So far, the FDLQI has been used in family members of patients with psoriasis^{23,25}, vitiligo²⁴, epidermolysis bullosa¹⁷, leg ulcers²², atopic dermatitis²⁰ and to measure the effect of cosmetic camouflage²¹. Validity, reliability, and responsiveness of the FDLQI have been extensively studied. It can be completed very quickly, since it has only ten items, and it has been translated into several languages. However, score descriptor categories and meaning of score change have still to be defined.

More recently, in order to gain more information on the impact of a specific skin condition on family and caregivers, disease-specific instruments have been developed. These include the PFI and the FamilyPso for psoriasis, the EB-BoD for epidermolysis bullosa, and the FBI for ichthyosis. Up to now, they have been rarely used, and many of their properties still need to be evaluated. However, they may potentially be useful to detect the specific impairment due to a particular disease, and so it is important to be aware of their existence. Family member QoL instruments designed and validated for use specifically in one disease should not be used in a different skin disease, as the impact of different diseases may have subtle differences⁸.

This paper follows three papers published by the EADV Taskforce on Quality of Life: the first concerned measurement instruments in adult patients with skin disease⁷², the second concerned the measurement of health-related QoL in children with skin disease⁷³, and the third described the potential benefits of measuring QoL in routine clinical practice⁷⁴. One aim of the Taskforce is to outline principles for the measurement of health-related QoL in

dermatological research and practice. In the first paper ⁶⁹, the Taskforce described the psychometric properties which an instrument should meet to be used in clinical research or practice, i.e., scale structure, reliability, validity and responsiveness. Family QoL instruments should obviously also meet the same criteria. We have identified satisfactory aspects of validation of some generic and disease-specific instruments, but for most instruments various aspects of validation still need to be studied.

We did not identify any information concerning the use of these measures in routine clinical practice. However it is potentially possible that the use of such measures in certain clinical situations might be of benefit, as has been suggested concerning the routine use of QoL measures designed for patients ⁷⁴.

Conclusions

This review has identified nine instruments that are designed to measure the impact on the lives of family members, partners and carers of having someone in the family with a skin disease. The ability to measure this largely hidden impact is the first step in being able to more fully understand the impact. This has the potential to encourage the development of strategies to address these issues and support those affected, and to measure the effectiveness of attempts at intervention.

EADV Task Force on Quality of Life recommendations

The EADV Taskforce on Quality of Life makes the following recommendations concerning the instruments measuring health-related QoL in family and caregivers of patients with skin disease:

1. The measurement of the impact of a skin disease on family and caregivers should be included in a thorough evaluation of the burden of the disease.

2. To choose the most appropriate instrument, it is important first to have clarity in the aim of a study. If the aim is to have details on the impact of a particular skin disease, a disease-specific questionnaire should be chosen. On the other hand, use of a generic instrument will allow comparison of the impact of a particular disease with the impact of other diseases.
3. Before using an instrument, it is important to verify if a validated translated version exists for the population to be studied. Otherwise, the study may be an opportunity to validate a new translated version, following standard validated translation guidelines.
4. Before using an instrument for research, it is important to verify whether properties such as scale structure, validity, reliability, and responsiveness have been evaluated. If not, consider whether any of these properties could be evaluated in the proposed new study.

Table 1. Evaluation table for the properties of the measurement instruments

| Characteristics | Definitions | Grades and criteria | | |
|--|--|---|--|---|
| Validity 1. Conceptual 2. Construct 3. Convergent | Does the tool measure what it is supposed to measure? Are the relevant domains captured? Does tool confirm hypothesized difference (e.g., diagnosis, clinical disease severity..) Does the tool relate to other tools measuring the same construct? | 1. A: well balanced objective and subjective domains B: more focused on objective or subjective domains C: missing important quality of life domains | 2. A: >75% of results are in accordance with specific hypothesis B: <75% of results are in accordance with specific hypotheses C: no information | 3. A: correlation >0.70 B: correlation <0.70 C: no information |
| Interpretability 1. Norms 2. Categorization 3. MCID (Minimal Clinically Important Difference) | Are there standard comparative data from the general population and/or dermatology patients published and/or available? Are there categories of the obtained score available? Has the minimal change that is relevant to patients been reported? | 1. A: general and dermatology patients B: general or dermatology patients C: general nor dermatology patients | 2. A: using anchor or banding techniques B: using distribution based techniques C: not reported | 3. A: MCID is known in heterogeneous sample B: MCID is known in limited sample C: not reported |
| Reliability 1. Internal consistency 2. Retest-reliability (ICC= intraclass correlation coefficient) | Does the tool provide a consistent answer? The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct (Cronbach's α)? Does a repeated administration of the tool within a reasonable period result in a similar outcome? | 1. A: $0.95 > \text{Cronbach's } \alpha > 0.70$ B: $\text{Cronbach's } \alpha < 0.7$ or > 0.95 C: $\text{Cronbach's } \alpha$ not reported | 2. A: k or $\text{ICC} > 0.7$ B: k or $\text{ICC} < 0.7$ or correlation coefficients > 0.7 C: k or ICC not reported or correlation coefficient < 0.7 | |
| Structure | Have the domains and/or summary score of the tool been confirmed? | A: item response theory B: factor analysis C: no factor analysis or item response theory | | |
| Responsiveness | Is the tool sensitive to detect changes over time or due to therapy using patient centered and/or clinical criteria? | A: strong B: moderate or conflicting evidence C: absent, weak, or solely based on statistical evidence | | |
| Item bias | Do the items of the tool function similar across external factors such as age, gender, and diagnosis? | A: strong B: moderate or conflicting evidence C: absent or weak | | |
| Cultural issues 1. Translations 2. Cultural equivalence | Has the tool been translated using guidelines? Has the tool been analysed in a cultural equivalence study? | 1. A: always B: sometimes C: never, not reported | 2. A: always B: sometimes C: never | |
| Respondent burden | Is the length and content acceptable to the patient? | A: brief (<15 min) B: long or problems of acceptability C: long and problems of acceptability | | |
| Administrative burden | How easy is the tool to administer, score and interpret? | A: simple B: moderate C: complex | | |
| Alternative forms | Is the tool available and tested for alternate forms of administration such as interviews in person or telephone, self-administration or computer-assisted interviews. | A: strong evidence B: moderate or conflicting evidence C: absent or weak evidence | | |

Table 2. Evaluation of the family quality of life questionnaires according to the guidelines given in Table 1.

| | Family Dermatology Life Quality Index (FDLQI) | Dermatitis Family Index (DFI) | Parents' Index Qol Atopic Dermatitis (PiQoL-AD) | QoL in primary caregivers of children with atopic dermatitis (QPCAD) | Childhood Atopic Dermatitis Impact Scale (CADIS) | Psoriasis Family Index (PFI) | FamilyPso | Epidermolysis Bullosa Burden of Disease (EB-BoD) | Family Burden Ichthyosis (FBI) |
|------------------------------|---|-------------------------------|---|--|--|------------------------------|-----------|--|--------------------------------|
| Validity | | | | | | | | | |
| Conceptual | A | A | B | B | A | A | B | A | A |
| Construct | A | A/B | A | B | A | A | C | B | B |
| Convergent | B | A | B | B | B | C | A/B | B | B |
| | | | | | | | | | |
| Interpretability | | | | | | | | | |
| Norms | C | C | C | C | C | C | C | C | C |
| Categorization | C | B | C | C | C | C | C | C | C |
| MCID | C | C | A | C | C | C | C | C | C |
| | | | | | | | | | |
| Reliability | | | | | | | | | |
| Internal consistency | A | A | A | A/B | A | A | A | A | A |
| Retest reliability | A | A | A | A | A | A | C | A | C |
| | | | | | | | | | |
| Structure | B | C | A | B | A | A | B | B | C |
| Responsiveness | A | A | A | B | A | C | C | C | C |
| Item bias | C | C | A | C | C | A | C | C | C |
| | | | | | | | | | |
| Cultural issues | | | | | | | | | |
| Translations | A | A | A | C | B | B | C | B | B |
| Cultural equivalence | C | B | C | C | C | C | C | C | C |
| | | | | | | | | | |
| Respondent burden | A | A | A | A | B | A | A | B | B |
| Administrative burden | A | A | A | B | B | A | A | B | B |
| Alternative forms | C | C | C | B | C | C | C | C | C |

Table 3. Characteristics of the family quality of life questionnaires.

| | Family Dermatology Life Quality Index (FDLQI) | Dermatitis Family Index (DFI) | Parents' Index Qol Atopic Dermatitis (PiQoL-AD) | QoL in primary caregivers of children with atopic dermatitis (QPCAD) | Childhood Atopic Dermatitis Impact Scale (CADIS) | Psoriasis Family Index (PFI) | FamilyPso | Epidermolysis Bullosa Burden of Disease (EB-BoD) | Family Burden Ichthyosis (FBI) |
|-------------------------|---|--|---|--|---|---|---|---|---|
| References | 15,16 | 26,27 | 50,51 | 54 | 56,57 | 58-60 | 62 | 63 | 64 |
| Condition | All dermatological | Atopic dermatitis | Atopic dermatitis | Atopic dermatitis | Atopic dermatitis | Psoriasis | Psoriasis | Epidermolysis Bullosa | Ichthyosis |
| Country | UK | UK | UK, The Netherlands, Germany, Italy, Spain, France, US, Switzerland | Japan | US | UK | Germany | France | France |
| Number of items | 10 | 10 | 28 | 19 | 45 | 14 | 15 | 20 | 25 |
| Possible answers | 4-point scale: not at all/not applicable, a little, quite a lot, very much. (0-3) | 4-point scale: not at all, a little, a lot, very much. (0-3) | Not reported | 5-point scale, from "none" to "extremely". (0-4) | 5-point scale, from "never" to "all the time". (0-4) | 4-point scale: not at all, a little, a lot, very much. (0-3) | 5-point scale: not true, somewhat true, moderately true, quite true, very true. (0-4) | 7-point scale: always, very often, often, sometimes, rarely, never, not applicable. | 4-point scale: definitely yes, maybe, definitely not, I don't know. |
| Domains | Emotional and physical wellbeing, relationships, social life, leisure activities, burden of care, | Housework, food preparation and feeding, sleep, family leisure activities, time spent on | Needs that can be influenced by a child having atopic dermatitis (e.g., need for child to have a safe and | Exhaustion (7 items), worry about atopic dermatitis (6 items), family cooperation (3 items), and achievement | Five domains, three of whom refer to the impact on the family: family and social function, sleep, and | Feelings of embarrassment, frustration, worry about the reaction of other people, worry about their future, | Emotional impact of the disease (emotional domain, ED), impact on daily activities | Family life (7 questions), child's life (3), disease and treatment (5), and economic and social impact (5). | Pain, daily life, familial and personal relationships, work and |

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|--|---|--|--|------------|-----------|---|--|--|-----------------------|
| | impact on job/study, housework and expenditure. | shopping for the family, expenditure, tiredness, emotional distress, relationships between the main carer and partner or between the main carer and other children and helping with treatment. | successful future, need for rest and relaxation, need for self-respect, need for independence) | (3 items). | emotions. | relationships, housework due to psoriasis and to treatment, time spent on treatment, social life, sporting activities, leisure activities, type of clothes, routine shopping and sleep. | and work or school and treatment characteristics (social domain, SD), and influence on leisure activities and personal relationships (leisure domain, LD). | | psychological impact. |
|--|---|--|--|------------|-----------|---|--|--|-----------------------|

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