

Quality of Life Measures in Atopic Dermatitis Clinical Care and Research

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HOME Core Measures

- Signs
 - Symptoms
 - Long term control
 - Quality of life
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- Initially it was unclear whether or not QOL should be included in the core set of domains
 - At the HOME II consensus meeting in Amsterdam in June 2011, core measures were finalized and included QOL

Health Related Quality of Life

- A patient's evaluation of the impact of disease and treatment on their physical, psychological and social functioning and well-being
- Often a secondary outcome measure and is increasingly becoming a primary endpoint
- QOL assessments will be integrated in measuring the quality of provided care

QOL Assessments

- Generic Health
 - i.e. SF-36, NHP
- Dermatology Specific
 - i.e. DLQI, DQOLS
- Disease Specific
 - i.e. MELASQOL, QoLIAD

What's the Problem

- Although there are a variety of quality of life measures used in atopic dermatitis research, no systematic review of these assessments has yet been performed
- Both generic and disease specific assessments exist and it is unclear which assessments and how many should routinely be used

Our Goal

- Provide a focused analysis of the content and measurement properties of the most frequently used QOL instruments in AD
- Using information regarding psychometric properties and instrument characteristics, formulate recommendations for the most appropriate QOL scale(s) for clinical care and research

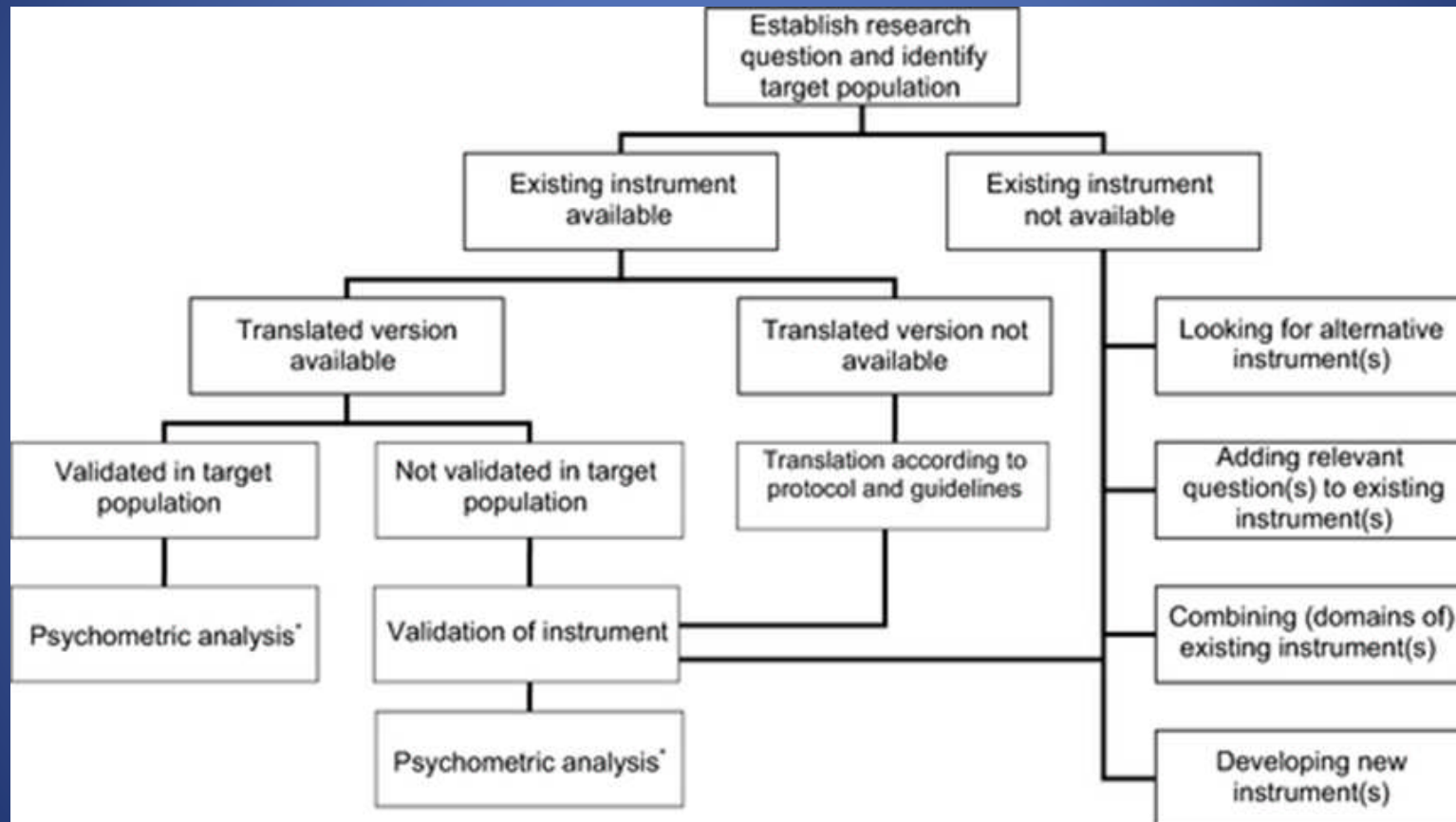
EADV Taskforce on QOL

- The European Academy for Dermatology and Venereology (EADV) Taskforce on Quality of Life was established in 2008 by Prof. A.Y. Finlay and Dr. T. Schaefer
- This taskforce encourages the use of QOL instruments in clinical care and research and provides information on the psychometric characteristics of these instruments

Psychometric Characteristics

- **Scale structure:** The extent to which items belong together, represent a particular domain of a certain construct
- **Reliability:** Measurement precision
- **Validity:** The degree to which the instrument actually measures what it is intended to measure
- **Responsiveness:** The extent to which the score of an instrument changes as a patient's condition changes over time
- **Interpretability:** The ability to interpret the significance of the results of an instrument in terms of a qualitative meaning to quantitative results

How to Choose a QOL Assessment



EADV Recommendations

- Clinical research: use a combination of generic and dermatology-specific instruments
- Clinical practice: Use dermatology-specific instrument as generic instruments might fail in the assessment of important dermatology-specific aspects
- Developing a new instrument should not be a priority as this is difficult, time consuming and does not contribute to the body of knowledge of existing instruments

Consensus-based Standards for the selection of health Measurement Instruments (COSMIN)

- Checklist for evaluating the quality of a study on measurement properties of a HR-PRO instrument, NOT for evaluating the quality of the instrument itself
- If the results of high quality studies differ from the results of low-quality studies, this can indicate bias

COSMIN Checklist

- **Internal consistency:** The degree of interrelatedness among the items
- **Reliability:** The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions
- **Measurement error:** The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
- **Content validity:** The degree to which the content of an HR-PRO instrument is an adequate reflection of the construct to be measured
- **Construct validity:** The degree to which the scores of an HR-PRO instrument are consistent with hypotheses
- **Criterion validity:** The degree to which the scores of an HR-PRO instrument are an adequate reflection of a "gold standard"
- **Responsiveness:** The ability of an HR-PRO instrument to detect change over time in the construct to be measured
- **Interpretability:** The degree to which one can assign qualitative meaning to an instrument's quantitative scores or change in scores

How We Arrived at Our Short List

- Using the EADV Taskforce recommendations and the COSMIN checklist as a guideline, we started with a broad literature search to find the most commonly used QOL assessments in AD literature
 - **Lit Search 1:** Atopic Dermatitis AND Quality of Life
- We then performed a more systematic search to find articles evaluating the psychometric properties of these QOL tools
 - **Lit Search 2:** Atopic Dermatitis AND Quality of Life AND Questionnaire OR Instrument OR Test OR Inventory OR Scale OR Index OR Survey
- In addition, we searched for some of the selected assessments by name to review their validation
- We chose to take a more pragmatic approach and focus on assessments that are already validated and commonly used as these will be more likely to be universally accepted and put into both clinical care and research practices

Most Commonly Used QOL Assessments in AD

- **Generic:**
 - EuroQol Quality of Life Scale (EQ-5D)
 - Medical Outcomes Short Form-36 Health Survey (SF-36)
- **Dermatology Specific:**
 - Dermatology Life Quality Index (DLQI)
 - Children's Dermatology Life Quality Index (CDLQI)
 - Skindex – 29
- **Disease Specific:**
 - Infant's Dermatitis Quality of Life (IDQoL) Index
 - Childhood Atopic Dermatitis Impact Scale (CADIS)
 - Quality of Life Index for Atopic Dermatitis (QoLIAD)
 - Dermatitis Family Impact (DFI) [Family]

Table 2. Quality of life scales.

Scale	Questions										# Studies used in	
	Severity	itching	mood	sleep	dressing/ clothes	leisure activities	treatment	Parent mood	Parent sleep	family disruption/ tension		
Children's Dermatology Life Quality Index (CDLQI)		*	*	*	*	*	*					13
Dermatology Life Quality Index (DLQI)		*	*		*	*	*					8
Infant's Dermatology Quality of Life (IDQOL)	*	*	*	*	*	*	*					7
Dermatitis Family Impact (DFI)				*		*		*	*	*		6
Parent's Index of Quality of Life in Atopic Dermatitis (PIQoL-AD)					*		*	*	*	*		2
Quality of Life Index for Atopic Dermatitis (QoLIAD)			*		*	*						2
Short Form Health Survey (SF-36)			*		*	*						2
Parents of Children with Atopic Dermatitis (PQoL-AD)								*	*			1
German Instrument for the assessment of Quality of Life in Skin Diseases (DIELH)		*	*			*	*					1
Eczema Disability Index (EDI)						*	*					1
Skindex-29		*	*	*		*						1

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Rehal B, Armstrong A (2011) Health Outcome Measures in Atopic Dermatitis: A Systematic Review of Trends in Disease Severity and Quality-of-Life Instruments 1985–2010. PLoS ONE 6(4): e17520. doi:10.1371/journal.pone.0017520
<http://www.plosone.org/article/info:doi/10.1371/journal.pone.0017520>

Generic HR-QOL Assessments

EuroQol Quality of Life Scale (EQ-5D)

- Description
 - Five items, including a visual analog scale
 - Three domains: Physical, Mental and Social Functioning
- Pros
 - Takes one minute to complete
- Cons
 - Not very sensitive to differences associated with minor morbidity such as skin diseases

Medical Outcomes Study Short Form-36 Health Survey (SF-36)

- Description
 - Most commonly used generic HRQOL instrument
 - 36 items
 - 8 domains: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems and mental health
 - Physical Component Score (PCS) and Mental Component Score (MCS)
 - Total score from 0 (worst) -100 (best)
- Pros
 - Internal consistency, test/retest reliability, construct validity and responsiveness have been tested (not all in AD patients)
 - In AD, construct validity has been tested, MCS correlates with disease severity (EASI and SCORAD)
 - Also in AD, +/- Responsiveness
- Cons
 - Takes 5 minutes to complete (shorter versions exist SF-12, 8 and 6D)
 - PCS does not correlate with disease severity (not sensitive to physical disability caused by AD)

Dermatology Specific HR-QOL Assessments

Dermatology Life Quality Index (DLQI)

- Description
 - Most commonly used QOL tool in dermatology
 - 10 items which focus on 6 dimensions: 'symptoms', 'daily activities', 'leisure', 'work', 'personal relationships' and 'treatment.'
 - Total score between 0 (best) and 30 (worst)
- Pros
 - Internal consistency and test/retest reliability, construct validity, responsiveness and interpretability have been tested (not all in AD)
 - Responsiveness and construct validity tested in AD (Correlates with disease severity, EASI, SCORAD)
 - Takes 2 minutes to complete
- Cons
 - May be gender differences (some scores correlate more for women than men mostly in regards to visible disease)
 - New analysis has shown there may be misfitting items, differential item functioning by disease, age and gender, disordered response threshold and inadequate measurement of mild disease

Children's Dermatology Life Quality Index (CDLQI)

- Description
 - 10 written questions, each with four possible replies scored 0 to 3
 - Overall score of 0 (best) 30 (worst)
- Pros
 - Reliability, content validity and responsiveness have been tested
 - Takes approximately 2 minutes to complete
 - New pictorial version is available (more child friendly)
- Cons
 - Correlation with disease severity is controversial

Trouble with Skin

The aim of the questionnaire is to measure how much your skin problem has affected you OVER THE LAST WEEK. Please tick ✓ one box for each question.

OVER THE LAST WEEK

Very much

Quite a lot

A little

Not at all



How itchy, 'scratchy', sore or painful has your skin been ?

OVER THE LAST WEEK

Very much

Quite a lot

A little

Not at all



How upset or embarrassed, self conscious or sad have you been because of your skin?

Skindex-29

- Description
 - 29 items
 - Multi-dimensional QOL instrument plus one extra item on adverse effects of treatment
 - Three domains: Symptoms, Emotions, Functioning
- Pros
 - Internal consistency, test/retest reliability, construct validity, content validity, responsiveness, interpretability were tested (not all in AD specifically)
 - Validity and reliability have been tested in AD
- Cons
 - Takes 5 minutes to complete, shorter versions exist (Skindex-17)

Disease Specific HR-QOL Assessments

Infant's Dermatitis Quality of Life (IDQoL) Index

- Description
 - Specifically suited to children aged ≤ 4
 - 10 questions addressing symptoms and difficulties with mood, sleep (2 questions), play, family activities, mealtimes, treatments, dressing and bathing
 - Score 0-3 for each question, overall score 0 (best) to 30 (worst)
 - Maximum overall score is 30 (higher scores reflecting greater impairment)
- Pros
 - Test/re-test reliability has been tested
 - +/- Responsiveness
 - Takes approximately 2 minutes to complete
- Cons
 - Correlation with disease severity is controversial

Childhood Atopic Dermatitis Impact Scale (CADIS)

- Description
 - Specific for children younger than 6 years and their parents
 - 45 items
 - Score 0-180
 - 5 domains: Child Symptoms, Child Activity Limitations and Behavior, Family and Social Function, Parent Sleep, and Parent Emotions
- Pros
 - Internal consistency, content validity, test-retest reliability, concurrent validity, discriminative validity, responsiveness have been tested
- Cons
 - Takes 6 minutes to complete (shorter version was used in an Italian study and showed good psychometric properties)

Quality of Life Index for Atopic Dermatitis (QoLIAD)

- Description
 - Created using a needs based model
 - 25 items
 - Score ranges from 0 (best)-25 (worst)
- Pros
 - Test/retest reliability, internal consistency, construct validity have been tested
 - Takes approximately 2 minutes to complete
- Cons
 - Did not have a good coefficient for test-retest reliability or correlation with parent perceived severity in patients pooled from Netherlands

Dermatitis Family Impact (DFI)

- Description
 - One-page questionnaire measures extent to which child with AD affects QOL of family
 - 10 items
 - Each question has four responses: not at all = 0, a little = 1, a lot = 2 and very much = 3.
 - Overall score 0 (best) to 30 (worst)
- Pros
 - Reliability, validity (construct validity) and responsiveness have been tested
 - Correlates with EASI
 - Takes 2 minutes to complete
- Cons
 - Correlation with SCORAD is controversial

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