SYSTEMATIC REVIEW

Assessment of stigma related to visible skin diseases: a systematic review and evaluation of patient-reported outcome measures

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Abstract
Misconceptions about visible skin diseases are widespread, and patients often face discrimination and stigmatization due to their condition. The associated negative health and psychosocial consequences of stigmatization in skin diseases have prompted an increase in research activity in recent times, resulting in a wide variety of assessment measures. This study aimed at aggregating and evaluating evidence of psychometric properties and methodological quality of published measures to assess stigma in visible skin diseases. Studies assessing stigmatization in visible skin diseases were searched in four databases (Medline, PsycINFO, Web of Science and Embase) until February 2021. The review followed PRISMA guidelines. Papers regarding development and/or validation of measures were identified by two independent researchers. Inclusion criteria were defined as follows: (i) quantitative studies in (ii) populations with skin diseases using (iii) questionnaires explicitly assessing (iv) perceived or public stigmatization or discrimination available in (iv) English or German language. The COnsensus-based Standards of health Measurement INstruments (COSMIN) checklist was used to evaluate their psychometric properties and risk of bias. 35 studies using 21 instruments were identified. Twenty instruments focused on assessing the perceived reality of those affected by visible skin diseases, while public stigma was only assessed by two instruments. Twelve scales could be recommended for use, while nine instruments had the potential to be recommended after further studies have assessed their quality. Some limitations are to be noted. Only studies in English and German were included. Research on self-constructed instruments can lead to new validated instruments, but they were not included in the review at this point. Several validated instruments could be recommended for use. Future research is needed regarding the assessment of stigma across different visible skin diseases, in children and adolescents, and in the general public.

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Introduction
Skin disease is prevalent in more than a quarter of the population worldwide1 and one of the leading causes of disability.2 Patients with skin diseases are burdened not only by physical symptoms and comorbidities but also by psychosocial impairment. Health-related quality of life is negatively affected,3 and psychological disorders such as depression but also feelings of stigmatization are frequent in dermatology patients.4,5

Stigma is a multifaceted construct, and its conceptualization has evolved over time.6,7 Frequently, conceptualizations of stigma differentiate between public stigma and self-stigma, with the latter referring to self-stigmatization due to internalized stereotypes and prejudices and the former describing stigmatization...
and discrimination against a group of people based on stereotypes and prejudices. Alternative models of stigma originating in the fields of psychology and sociology have coined the additional terms of enacted stigma and felt stigma. According to these conceptualizations, the stigmatized individual is affected by public stigma in different ways: through self-stigma (as previously defined), through felt stigma and through enacted stigma. Felt stigma describes an internal experience and encompasses knowledge and expectations about the probability that stigmatization could occur in a given situation and the possibility of accompanying feelings of dread and fear in anticipation of social rejection. Enacted stigma describes any externally stigmatizing reaction that would result in the stigmatized individual being treated unfairly or negatively and includes both discrimination (e.g. being denied a job) and subtle forms of social devaluation, for example patronization, harsh treatment or social avoidance of the person with the stigmatized condition. Similarly, a recent conceptual model of stigma in visible skin diseases includes an external and an internal stigma dimension, while also taking the relationship between these dimensions, socio-demographic and disease characteristics, and the impact of stigma into account.

Due to the visibility of their condition and widespread misconceptions, individuals with skin diseases are frequently confronted with stigmatization and discrimination not just in adulthood but also in childhood and adolescence. These experiences often lead to people accepting and internalizing stigmatizing attitudes, resulting in, for example, low self-esteem and social withdrawal. Stigmatization has been found to impair mental health, quality of life and life satisfaction – even independently of objective burden of the disease. Assessing felt and enacted stigma is therefore important to identify the magnitude of the problem not only in individuals themselves but also in the general public. While for some skin diseases, such as Hansen’s disease, a bodyblem not only in individuals themselves but also in the general public but also in childhood and adolescence. These experiences often lead to people accepting and internalizing stigmatizing attitudes resulting in, for example, low self-esteem and social withdrawal. Stigmatization has been found to impair mental health, quality of life and life satisfaction – even independently of objective burden of the disease. Assessing felt and enacted stigma is therefore important to identify the magnitude of the problem not only in individuals themselves but also in the general public. While for some skin diseases, such as Hansen’s disease, a body.

The increase in research activity for the topic of stigmatization in dermatology has led to the development and application of a wide variety of assessment measures over time. To gain a more detailed understanding of the nature, degree and impact of stigmatization in individuals with visible skin diseases, valid and reliable assessment tools are necessary and a summarizing overview regarding the strengths and limitations of existing measures is essential. One previous review summarized stigma instruments for visible skin diseases in 2017 but did not use a systematic search approach nor conducted an evaluation of studies and instruments. This review will therefore be the first to use the COmmon Research Model (COSMIN) guidelines to (i) aggregate and (ii) evaluate evidence of psychometric properties and methodological quality of existing measures used to assess stigma in visible skin diseases.

Methods
This review follows all proposed steps of the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), but did not include a registered protocol. As the aim was to evaluate the published patient-reported outcome measures (PROMs), this first section also follows steps provided by the COSMIN guidelines.

Literature search
Part A is defined as the necessary literature research and is consistent with the PRISMA approach. The aim of the review was to find all PROMs that are used to assess stigmatization in visible skin diseases. Therefore, the search strategy of the COSMIN manual was applied and a three-component search string divided into construct, population and instrument was used. The search string can be found in Appendix 1. Inclusion criteria were defined as follows: (i) qualitative studies in (ii) populations with skin diseases using (iii) questionnaires explicitly assessing (iv) perceived or public stigmatization or discrimination available in (iv) English or German language. Qualitative studies, studies that used generic quality-of-life instruments while not detailing specific subscales for stigmatization and opinion papers, and reviews were excluded. Reference lists of articles were screened to identify additional relevant articles, especially if summarized in review articles.

Four databases (MEDLINE, Web of Science, PsycINFO and Embase) were searched until February 2021. Inclusion criteria were applied to screen title and abstracts of all articles found in the searches by two independent reviewers. After the initial screening, full texts were analysed, and all inclusion criteria were reapplied. In this process, all instruments used were identified, including self-constructed scales. All remaining studies were then screened to assess whether they used validated instruments and, if not yet included, searched for the original manuscript in instrument development. Inclusion criteria had to be reapplied to determine whether scales explicitly addressing stigma were contained in the instrument. Upon inclusion of relevant articles, data were extracted regarding development of each individual instrument (e.g. characteristics of the sample, assessment of stigma, scale properties and psychometric properties).

Evaluation of measurement properties
In the second component of this review, we used COSMIN as a guideline for data extraction. COSMIN section B (COSMIN Risk of Bias checklist) aims to provide an evaluation of content
validity, internal structure and other measurement properties, such as reliability, hypothesis testing. These data were extracted from all studies reporting a validation of the PROM. The checklist contains 10 steps, including content validity (steps 1 and 2), internal structure (steps 3–5) and remaining measurement properties (6–10). All properties are rated on a 4-point scale: ‘very good’, ‘adequate’, ‘doubtful’ or ‘inadequate’, and the lowest score determines the quality of the study.

In steps 1 and 2, content validity is assessed. COSMIN provides a separate manual for the assessment of content validity, which was used in this review. There, 10 criteria for good content validity are postulated including the dimension of relevance, comprehensiveness and comprehensibility. In line with this, content validity was assessed by two researchers prior to the detailed evaluation. In steps 3 through 10, COSMIN guidelines assess structural validity, internal consistency, reliability, measurement error, hypothesis testing for construct validity, cross-cultural validity, criterion validity and responsiveness, whereas steps 3–5 are part of the assessment of internal consistency. For each step, COSMIN formulates directions to come to a conclusion for the 4-point rating scale. For each measurement property, examples and references are given to aid the assessment. To determine structural validity, for example, COSMIN provides the following questions that were assessed in this review: firstly, studies are rated ‘very good’ if confirmatory factor analysis were performed; ‘adequate’ if exploratory factor analysis were performed; and ‘inadequate’ if neither was performed. Additionally, the sample sizes are rated ‘very good’: seven times the number of items and \( n \geq 100 \); ‘adequate’: five times the number of items and \( n \geq 100 \), or six times the number of items and \( n < 100 \); ‘doubtful’: five times the number of items, but \(<100\); or ‘inadequate’: \(<5\) times the number of items). Therefore, two questions are provided to guide the researcher to her decision. In this case, the overall rating is always the lowest score for any question.

Next, COSMIN provides an overview for criteria for good measurement properties (see Table 4 in COSMIN manual). After the risk of bias checklist assessing the quality of the study itself, the results are rated. For our example structural validity, this means that the manual specifically postulates that results are ‘sufficient’ (indicated by \( + \)) if model fits of confirmatory factor analysis reach a level of certainty that is acceptable (CFI or TLI or comparable measure \( \geq 0.95 \) OR RMSEA \( <0.06 \) OR SRMR \( <0.08 \)). If these criteria are not met, the results are rated insufficient (\( – \)). All results that are lacking information are rated indeterminate (\( ? \)). Again, examples and criteria are specifically detailed in the manual.

### Selection of PROMs

Part C of the COSMIN guidelines includes an algorithm to formulate recommendations based on the evaluation conducted in Part B. These recommendations rely on the described main criteria of content validity and internal consistency. Three categories are proposed:

A PROMs with evidence for sufficient content validity (any level) AND at least low-quality evidence for sufficient internal consistency.

B PROMs categorized not in A or C.

C PROMs with high-quality evidence for an insufficient measurement property.

### Results

#### Literature search

Figure 1 summarizes the number of included studies with detailed reasons for exclusion. It was decided to screen each database separately and remove duplicates only at the final stage of study inclusion, and therefore, the process was documented for each database.

We identified 3,348 abstracts for screening (see Fig. 1 for details) and included 397 papers for further investigation. Inclusion criteria were applied twice: firstly, all papers were screened, leading to exclusion of \( n = 179 \) articles. In this screening process, we identified \( n = 25 \) further eligible articles from reference lists. A total of 243 articles then entered the detailed full-text analysis. Of these, 208 were excluded. Reasons for exclusion are detailed in Fig. 1 (PROM-only outcome measure, self-constructed scales, single-item measures, duplicates, etc.).

After full-text analysis, we included \( n = 35 \) studies that used 21 different instruments (Tables 1 and 2).

#### Characteristics of instruments and studies

Twenty studies focused on assessing the felt reality of patients and those affected by chronic visible skin diseases. They either assessed felt stigma, internalized stigma or social isolation/participation. Public stigma or social distance was only assessed by four scales in two studies. Target populations were mostly patients with leprosy/Hansen’s disease (\( n = 8 \)), psoriasis (\( n = 4 \)) and burns (\( n = 3 \)). Most instruments were developed in English and subsequently validated for use in other languages. Except for one instrument, all instruments were validated to assess adults. Table 2 summarizes details from all 35 validation studies. More than one validation study was found for the DISABKIDS measure (\( n = 2 \)), the EMIC community stigma scale and EMIC stigma scale (\( n = 2 \), the Feelings of Stigmatization Scale (FSQ, \( n = 3 \)), the Impact of Chronic Skin Disease Daily Life (ISDL) Stigma sub-scale (also referred to as the 6-item stigmascaling in later publications, \( n = 2 \)), the P-Scale (\( n = 4 \)), the Perceived Stigmatization Questionnaire (PSQ, \( n = 4 \)), the Social comfort questionnaire (SCQ, \( n = 4 \)) and the Questionnaire on Experience of Skin Complaints-Short Form (QES-SF, \( n = 2 \)). It is noteworthy that PSQ and SCQ were always reported back to back in studies, but sometimes as two instruments and sometimes as one instrument with the SCQ representing a separate scale. For clarity reasons, both scales are reported separately. Sample sizes varied considerably, ranging from 39 to 5,125.
Evaluation of instruments and recommendation

Tables 3 and 4 summarize the findings regarding the evaluation of all PROMs. Measurement error and criterion validity were not reported in any of the studies and were therefore not included in the overview. For the majority of the evaluated studies, information on structural validity, internal consistency and the testing of hypotheses was available. Cross-cultural validity, reliability and responsiveness were only reported by some studies.

The summary of these findings is displayed in Table 5. Content validity was sufficient or inconsistent for all studies. Inconsistent rating resulted from the item ‘All key concepts are included’ from the dimension comprehensiveness. This was doubtful for some studies, and therefore, these received an ‘inconsistent’ rating.

Following COSMIN suggestions, the following PROMs received an ‘A’-rating and are therefore recommended for use: EMIC-CC and EMIC-CSS, FSQ, P-Scale and P-Scale Short, PSQ/SCQ, Podoconiosis Stigma Scale: Patients and Community, SWAP-PSI/PD, adapted SWAP-PSI and QES-SF. Other well-established instruments, such as the Social Distance Scale and the Scale for Internalized Stigma of Mental Illness (ISMI), lack validation for skin diseases specifically, and their internal structure has not yet been confirmed for this population. Others, such as the ISDL-stigma sub-scale/six-item scale or the DISAB-KIDS subscale, need to document content validity in a more detailed way.

Discussion

The aim of the current review was to identify and rate available validated instruments for the assessment of stigmatization in patients with visible skin diseases. 21 instruments were found, twelve of which can be recommended for use. All other instruments received a ‘B’-rating, meaning that they have the potential to be recommended, but need further studies to assess their quality. The large number of self-constructed scales (without development and validation studies) documents the importance of the topic and illustrates further directions of research.

Three aspects became obvious from our results: validated instruments are predominantly available for (i) Hansen’s disease, (ii) adults and (iii) concerning felt stigma of individuals affected by a visible skin disease. This is in line with previous findings.
| PROM (Ref) | Construct | Target population | Mode of administration | No. of items | Response options | Original language | Validated translations |
|-----------|-----------|------------------|------------------------|--------------|------------------|-------------------|---------------------|
| DISABKIDS A topic Dermatitis Module – Stigma subscale | Felt stigma | Atopic dermatitis | Self-report | 4 | 5-point Likert scale | English, German, French, Greek, Dutch, Swedish | Portuguese |
| EMIC Community Stigma Scale (EMIC-CSS) | Enacted stigma | Leprosy | Interview | 13, 15 | 4 options: yes, possibly, no and do not know | English, Indonesian, Tamil and Bengali | |
| EMIC Stigma Scale (EMIC-SS) | Felt stigma | Leprosy | Interview | 17 | 4 options: yes, possibly, no and do not know | English, Tamil and Bengali, Portuguese | |
| Feelings of Stigmatization Scale (FSQ) | Felt stigma | Psoriasis | Self-report | 33 | 6-point Likert scale | English | Arabic |
| Hairdex Stigma subscale | Felt stigma | Alopecia | Self-report | 8 | 5-point Likert scale | German | |
| Internalized Stigma of Mental Illness (ISMI) | Internalized stigma | Leprosy, psoriasis | Self-report | 28 | 4-point Likert scale | English, Tamil and Bengali, Turkish | |
| Impact of Chronic Skin Disease on Daily Life (ISDL) Stigma subscale | Felt stigma | General skin diseases | Self-report | 6 | 4-point Likert scale | English, Arabic | Arabic, Polish |
| Leprosy Internalised Stigma Scale (LISS) | Internalized stigma | Leprosy | Self-report | 27 | 4-point Likert scale | English | Bengali |
| OnyCOETM questionnaire – Stigma subscale | Felt stigma | toenail onychomycosis | Self-report | 7 | 5-point Likert scale | English | |
| Participation Scale (P-Scale) | Social participation | Leprosy | Interview-based | 18 | 4-point Likert scale | English, Arabic | Hindi, Bengali, Telugu and Tamil, Portuguese, Nepali, Twi, French |
| Participation Scale Short (P-Scale Short) | Social participation | Leprosy | Interview-based | 13 | 4-point Likert scale | English | Portuguese, German |
| Perceived Stigmatization Questionnaire (PSQ) | Felt stigma | Burn victims | Self-report | 38 | 5-point Likert scale | English, Amharic and Wolaitigna (Ethiopian languages) | |
| Podoconiosis Stigma Scale: Patients | Felt stigma | Podoconiosis | Self-report | 15 | 4 options: yes, possibly, no and do not know | Amharic and Wolaitigna (Ethiopian languages) | English |
| & Enacted stigma | Podoconiosis | Self-report/interview-based | 17 | 4 options: yes, possibly, no and do not know | Amharic and Wolaitigna (Ethiopian languages) | |
| Podoconiosis Stigma Scale: Community | Felt stigma | Podoconiosis | Self-report | 24 | 4 options: yes, possibly, no and do not know | Amharic and Wolaitigna (Ethiopian languages) | English |
| & Enacted stigma | Podoconiosis | Self-report/interview-based | 23 | 4 options: yes, possibly, no and do not know | Amharic and Wolaitigna (Ethiopian languages) | English |
| SARI Stigma Scale (SSS) | Felt stigma | Leprosy | Self-report | 22 | 4 options: yes, possibly, no, do not know and then 3 answer categories (always, sometimes and rarely/once) | Bahasa Indonesia | |
Table 1 Continued

| PROM (Ref)                                                                 | Construct                           | Target population | Mode of administration | No. of items | Response options                | Original language | Validated translations |
|--------------------------------------------------------------------------|-------------------------------------|-------------------|------------------------|--------------|--------------------------------|--------------------|-----------------------|
| Satisfaction With Appearance Scale – Perceived Social Impact and Social Comfort Questionnaire (SCQ)\(^2\) | Felt stigma                         | Scleroderma       | Self-report            | 7            | 7-point Likert scale           | English            | English, Portuguese, German |
| Social Distance Scale\(^3\)                                              | Social distance                     | Leprosy           | Self-report after vignette presentation | 7            | 4-point Likert scale           | English            | Indonesian        |
| Questionnaire on Experience of Skin Complaints-Short Form (QES-SF)\(^4\) | Felt stigma                         | Psoriasis, atopic dermatitis | Self-report          | 23           | 5-point Likert scale           | German             | English             |

Although the term “leprosy” is no longer used, we included the nomenclature used in the articles.

EMIC, explanatory model interview catalogue.
\(^1\)Study not available in English.
\(^2\)Exclusion of one item (mentally ill people tend to be violent).
\(^3\)Validation study only available in Turkish.
\(^4\)Based on Feelings of Stigmatization Questionnaire.
| PROM                                                                 | Ref | Disease                      | Population                              | Age Mean (SD, Range) yr | Gender, % female | Additional information                                                                 | Instrument administration | Setting                      | Country                      | Language       |
|----------------------------------------------------------------------|-----|------------------------------|-----------------------------------------|-------------------------|-----------------|----------------------------------------------------------------------------------------|------------------------------|-----------------------------|-----------------------------|----------------|---------|
| DISABKIDS Atopic Dermatitis Module – Stigma subscale                 | 32  | Atopic dermatitis            | Children and parents                    | 12.2 (2.8, 8-16)        | 52              | Date on age and gender are based on the whole sample of the study (n=1,152)             | Clinical sample              | Austria, France, Germany, Greece, Netherlands, Scotland, Sweden | English, German, French, Greek, Dutch, Swedish |                |
|                                                                      | 49  | Atopic dermatitis            | Convenience, non-probability sampling, equal distribution of sex and age group | 1: 96 (1.1, 8-12)       | 2: 144 (1.4, 13-18) | "similar" distribution                                                                 | Clinical sample              | Brazil                                   | Portuguese                   |                |
| EMIC Community Stigma Scale (EMIC-CSS)                                | 33  | Leprosy                      | Community members in Indonesia          | 42.1 (13.2, n.r.)       | 62.2            | Categorization of participants in 2 groups: 1: 8-12 years old 2: 13-18                   | Community-based             | Indonesia                                | Indonesian                   |                |
|                                                                      | 34  | Leprosy                      | Community members in India              | n.r.                    | n.r.            | No details on sample given                                                              | Community-based             | India                                     | Tamil and Bengali              |                |
| EMIC Stigma Scale (EMIC-SS)                                           | 34  | Leprosy                      | Community members in India              | n.r.                    | 50              | Half of the sample lived in community-based rehabilitation centres, differences in visibility from two different sites | Community-based             | India                                     | Tamil and Bengali              |                |
|                                                                      | 50  | Leprosy                      | Patients affected by leprosy, in treatment | 49.3 (15.1, 18-89)      | 31.7            | Exclusion of people with other stigmas, 87% response rate                               | Clinical sample              | Brazil                                    | Portuguese                   |                |
| Feelings of Stigmatization Scale (FSQ)                               | 35  | Psoriasis                    | Patients in treatment at study centre   | N.r. (n.r., 20-70)      | n.r.            | 75% moderate-to-severe disease, 85% response rate in hospitalized patients             | Clinical sample              | USA                                        | English                      |                |
|                                                                      | 51  | Psoriasis                    | Patients in Abu Dhabi                   | 36.3 (12.2, n.r.)       | 28              | Use of 32 item version                                                                   | Clinical sample              | United Arab Emirates                      | Arabic                       |                |
|                                                                      | 52  | Psoriasis, atopic dermatitis | Patients from clinic (Ps) or convenience sample (AD) | 39.1 (13.1, 14-80)     | 63.3            | Use of 32 item version                                                                   | Clinical sample              | Great Britain                             | English                      |                |
| Hairdex Stigma subscale                                              | 36  | Alopecia                     | Participants in treatment centre        | 42.3 (12.4, 19-66)      | 100             |                                                                                         | Treatment centre             | Germany                                   | German                       |                |
| Internalized Stigma of Mental Illness (ISIM)                         | 34  | Leprosy                      | Community members in India              | n.r.                    | 50              | Half of the sample lived in community-based rehabilitation centres, differences in visibility from two different sites | Community-based             | India                                     | Tamil and Bengali              |                |
| Impact of Chronic Skin Disease on Daily Life (ISD) Stigma subscale 6-item Stigma Scale | 37  | Psoriasis and atopic dermatitis | Patients in outpatient clinic          | 47.6 (14.6, 17-84)/35.0 (15.3, 16-77) | 60/69           |                                                                                         | Clinical sample              | Netherlands                               | Dutch                        |                |
|                                                                      | 51  | Psoriasis                    | Patients in Abu Dhabi                   | 36.3 (12.2, n.r.)       | 28              |                                                                                         | Clinical sample              | United Arab Emirates                      | Arabic                       |                |
| PROM                          | Ref | Disease          | Population                              | Age Mean (SD, Range) yr | Gender, % female | Additional information                                                                 | Instrument administration | Setting          | Country          | Language          |
|-------------------------------|-----|------------------|-----------------------------------------|-------------------------|-----------------|----------------------------------------------------------------------------------------|---------------------------|------------------|------------------|------------------|
| Leprosy-Internalised Stigma Scale (LISS) | 38  | Leprosy          | Hospitalized patients                   | 40.4 (14.2, 18-70)      | 38              | Clinical sample                                                                      | India                      | Bengali          |                  |                  |
| OnyCOE+™ questionnaire – Stigma sub-scale | 39  | Toenail onychomycosis | Patients in clinical trial Group 1: 48.4 (12.9, 18-75) Group 2: 49.9 (14.1, 18-75) | Group 1: 36 Group 2: 41 |                  | Undear number of centres, study report, n=90 participants from each centre             | Clinical sample           | USA              | English          |                  |
| Participation Scale (P-Scale) | 40  | Leprosy          | Centres in 3 countries (India, Nepal and Brazil) | n.r.                    | n.r.            | Half of the sample lived in community-based rehabilitation centres, differences in visibility from two different sites | Community-based           | India, Brazil and Nepal | Hindi, Bengali, Tdugu and Tamil, Portuguese, Nepalese |                  |
| Participation Scale Short (P-Scale Short) | 41  | Leprosy          | Multicounty database of previous studies | 44.1 (16.1, n.r.)       |                  | Clinical sample                                                                       | Ghana and Benin           | Twi and French |                  |                  |
| Perceived Stigmatization Questionnaire (PSQ) | 42  | Burns            | Members of all burn survivor support groups | 44.1 (13.6, n.r.)       |                  | Members of support groups                                                             | USA                       | English          |                  |                  |
| Podoconiosis Stigma Scale: Patients and Community | 43  | Podoconiosis     | People with podoconiosis in clinic sites, members of the community | N.r. only age categories Patient=54 Community=42.2 |                  | Mixed sample                                                                           | Ethiopia                   | Amharic and Wolof |                  |                  |
| SARI Stigma Scale (SSS)       | 44  | Leprosy          | People with leprosy in treatment or released from treatment | 35 (13.9, 15-65)       |                  | Exclusion of 198 respondents due to different languages                                | Clinical sample           | Indonesia        | Bahasa Indonesia |                  |
| Satisfaction With Appearance Scale – Perceived Social Impaired and Social Discomfort subscales (SWAP-PSI/SD) | 45  | Burns            | Hospitalized burn victims                | 41.5 (14.7, n.r.)       |                  | Clinical sample                                                                       | USA                       | English          |                  |                  |
| PROM                                      | Ref | Disease            | Population                                                                 | N     | Patient selection                                                                 | Age Mean (SD, Range) yr | Gender, % female | Additional information                                                                                      | Instrument administration | Setting | Country | Language |
|-------------------------------------------|-----|--------------------|---------------------------------------------------------------------------|-------|-----------------------------------------------------------------------------------|-------------------------|-----------------|----------------------------------------------------------------------------------------------------------------|-----------------------------|----------|---------|----------|
| Adapted Satisfaction With Appearance      | 46  | Scleroderma        | Patients with limited or diffuse scleroderma                             | 254   |                                                                                  | 52.8 (12.9, 27-81)      | 85.5            | Part of a longitudinal study, samples of later waves also used in validation study                         | Clinical sample             | USA      | English |          |
| Scale - Perceived Social Impact subscale  |     |                    |                                                                           |       |                                                                                  |                          |                 |                                                                  |                             |          |         |          |
| SWAP-PSI                                  |     |                    |                                                                           |       |                                                                                  |                          |                 |                                                                  |                             |          |         |          |
| Social Comfort Questionnaire (SCQ)         | 42  | Burns              | Members of all burn survivor support groups                              | 361   |                                                                                  | 44.1 (13.6, n.r.)        | 52              | 23% response rate                                                                                         | Members of support groups  | USA      | English |          |
|                                            | 57  | Burns              | Brazilian burn victims in rehabilitation                                 | 240   |                                                                                  | 36.2 (10.9, n.r.)        | 53.3            | 98% response rate                                                                                         | Clinical sample            | Brazil   | Portuguese |          |
|                                            | 55  | Burns              | Hospitalized pediatric burn survivors                                    | 369   |                                                                                  | 13.5 (2.4, 8-16)         | 44              | Additional sample of parents (n=202)                                                                     | Clinical sample            | Brazil   | Portuguese |          |
|                                            | 56  | Burns              | Patients after hospitalization                                            | 139   |                                                                                  | 49.7 (15.2, 18-84)       | 35.3            | 18% response rate                                                                                         | Clinical sample            | Germany  | German |          |
| Questionnaire on Experience of Skin       | 47  | Psoriasis          | Consecutive patients in treatment centre                                 | 385   |                                                                                  | 49.3 (n.r., n.r.)         | 34.4            | 84% response rate                                                                                         | Clinical sample            | Germany  | German |          |
| Complaints (QES)                          |     |                    |                                                                           |       |                                                                                  |                          |                 |                                                                  |                             |          |         |          |
| Questionnaire on Experience of Skin       | 58  | Psoriasis, atopic dermatitis | Patients in treatment centres | 298 | Pso: 42.3 (15.5, 16-77) | Pso1: 42.1 (13.5, 15-75) | Pso2: 47.1 (12.1, 17-70) | 2 samples of patients with psoriasis                                                                 | Clinical sample            | Germany  | German |          |
| Complaints (QES) - 34 items               |     |                    |                                                                           |       |                                                                                  |                          |                 |                                                                  |                             |          |         |          |
| Questionnaire on Experience of Skin       | 48  | Psoriasis, atopic dermatitis | Inpatient patients | 463 | Pso women: 51.3 (12.4, 16-85) | Pso men: 46.2 (14.2, 16-85) | AD: 42 | Protocol from an RCT with different follow-ups (at 6-month follow-up inclusion of 827 protocols) | Clinical sample            | Germany  | German |          |
| Complaints-Short Form (QES-SF)            |     |                    |                                                                           |       |                                                                                  |                          |                 |                                                                  |                             |          |         |          |
|                                            | 59  | Psoriasis          | Trial patients                                                            | 1,005 |                                                                                  | n.r.                    | n.r.            | Protocol from an RCT with different follow-ups (at 6-month follow-up inclusion of 827 protocols)        | Clinical sample            | Germany  | German |          |

AD, atopic dermatitis; EMIC, Explanatory Model Interview Catalogue; n.r., not reported; Pso, psoriasis.
Table 3 Results of studies on measurement properties

| PROM (ref) | Language | Structural validity | Internal consistency | Cross-cultural validity | Reliability |
|------------|----------|---------------------|----------------------|------------------------|-------------|
| DISABKIDS Atopic Dermatitis Module – Stigma subscale | English, German, French, Greek, Dutch, Swedish | Adequate | EFA: 2 domains, stigma subscale shown (-) | Cronbach’s alpha Stigma subscale=0.71 (-) | N Meth qual Results (rating) |
| DISABKIDS Atopic Dermatitis Module – Stigma subscale | Portuguese | Very good | Cronbach’s alpha Stigma subscale=0.81 (-) | PSCI -0.17 (++) | N Meth qual Results (rating) |
| EMIC Community Stigma Scale (EMIC-CSS) | Indonesian | Adequate | EFA: 2 factor scale (strongly correlated, potential single higher-order factor) (?) | Cronbach’s alpha Stigma subscale=0.83 (-) | N Meth qual Results (rating) |
| EMIC Community Stigma Scale (EMIC-CSS) | Tamil and Bengali | Adequate | EFA: 2 factor scale after exclusion of 3 items (-) | Cronbach’s alpha Total=0.78 (+) F1=0.71 (+) F2=0.63 (-) | N Meth qual Results (rating) |
| EMIC Stigma Scale (EMIC-SS) | Tamil and Bengali | Very good | Cronbach’s alpha Total=0.88 (+) F1=0.81 (+) F2=0.91 (+) F3=0.79 (+) | Weighted kappa=0.70 (-) | N Meth qual Results (rating) |
| Feelings of Stigmatization Scale (FSQ) | Arabic | Inadequate | EFA: 6 Factor Scale (-) | Cronbach’s alpha F1=0.78 (+) F2=0.78 (+) F3=0.81 (+) F4=0.71 (+) F5=0.65 (-) F6=0.76 (-) | N Meth qual Results (rating) |
| Feelings of Stigmatization Questionnaire (FSQ) | English | Adequate | CFA: 2 factorscale after exclusion of 3 items (-) | Cronbach’s alpha F1=0.89 (+) F2=0.89 (+) F3=0.72 (+) | N Meth qual Results (rating) |
| Hairdex Stigma subscale | German | Adequate | Cronbach’s alpha F1=0.88 (+) F2=0.83 (+) F3=0.96 (+) F4=0.91 (+) F5=0.79 (+) | Weighted kappa=0.82 (-) | N Meth qual Results (rating) |
| Internalized Stigma of Mental Illness (ISMI) | Tamil and Bengali | Inadequate | Cronbach’s alpha F1=0.88 (+) F2=0.83 (+) F3=0.96 (+) F4=0.91 (+) F5=0.79 (+) | Retest product correlation r=0.84 (-) | N Meth qual Results (rating) |
| Impact of Chronic Skin Disease on Daily Life (ISDL) Stigma subscale/6-item Stigma Scale | Arabic | Inadequate | Cronbach’s alpha F1=0.88 (+) F2=0.83 (+) F3=0.96 (+) F4=0.91 (+) F5=0.79 (+) | ICC=0.84 (-) | N Meth qual Results (rating) |
| PROM (ref) | Language | Structural validity | Internal consistency | Cross-cultural validity | Reliability |
|-----------|----------|---------------------|----------------------|------------------------|-------------|
|           |          | N Meth qual Results (rating) | N Meth qual Results (rating) | N Meth qual Results (rating) | N Meth qual Results (rating) |
| Leprosy Internalised Stigma Scale (LISS) | Bengali | 416 Adequate EFA: 4-factor solution (?) | 416 Very good Cronbach's alpha Total=0.96 (+) F1=0.94 (+) F2=0.95 (+) F3=0.97 (+) F4=0.98 (+) | 416 Very good ICC=0.77 (+) |
| OnyCOE-tTM questionnaire – Stigma subscale | English | 504 Inadequate Based on theory (-) | 504 Very good Cronbach's alpha only reported to be between 0.84 and 0.91 (+) | |
| Participation Scale (P-Scale) | Hindi, Bengali, Telugu and Tamil, Portuguese, Nepalese | ? Indeterminate EFA: 1-factor scale (?) | ? Very good Cronbach's alpha-0.92 (+) | ? Very good No differences found between study centres (-) | ? Very good† Weighted kappa-0.83 (-) |
| Participation Scale (P-Scale) | Tamil and Bengali | 806 Very good Cronbach's alpha Total=0.92 (+) F1=0.83 (+) F2=0.92 (+) F3=0.95 (+) F4=0.98 (+) | 806 Very good | |
| Participation Scale (P-Scale) | Various | 5,125 Very good CFA: 2-factor solution (-) | 5,125 Very good Cronbach's alpha Total=0.93 (+) F1=0.83 (+) F2=0.92 (+) F3=0.95 (+) F4=0.98 (+) | |
| Perceived Stigmatization Questionnaire (PSQ) | English | 361 Very good CFA: 3-factor solution (-) | 361 Very good Cronbach's alpha F1=0.91 (+) F2=0.92 (+) F3=0.98 (+) | |
| Perceived Stigmatization Questionnaire (PSQ) | Portuguese | 240 Very good CFA: 3-factor solution (-), alterations to scale 3 EFA: 3-factor solution (-) | 240 Very good Cronbach's alpha Total=0.88 (+) F1=0.65 (+) F2=0.80 (+) F3=0.78 (+) | 240 Very good ICC Total=0.87 (+) F1=0.82 (+) F2=0.87 (+) F3=0.79 (+) |
| Perceived Stigmatization Questionnaire (PSQ) | Portuguese | 369 Very good CFA: 3-factor solution (-) | 369 Very good Cronbach's alpha F1=0.81 (+) F2=0.81 (+) F3=0.89 (+) | |
| Perceived Stigmatization Questionnaire (PSQ) | German | 146 Doubtful CFA: 3-factor solution (-) | 146 Very good Cronbach's alpha Total=0.86 (+) F1=0.90 (+) F2=0.84 (+) F3=0.71 (+) | |
| Podoconiosis Stigma Scale: Patients-felt Stigma | Amharic and Wolaitigna | 150 Adequate EFA: 1-factor solution (-) | 150 Very good Cronbach's alpha=0.87 (+) | |
| Podoconiosis Stigma Scale: Patients-enacted Stigma | Amharic and Wolaitigna | 150 Adequate EFA: 1-factor solution (-) | 150 Very good Cronbach's alpha=0.94 (+) | |
### Table 3 Continued

| PROM (ref)                                                                 | Language                                                                 | N   | Meth qual | Results (rating) | Internal consistency | Cross-cultural validity | Reliability        |
|--------------------------------------------------------------------------|--------------------------------------------------------------------------|-----|-----------|------------------|-----------------------|------------------------|---------------------|
| Podoconiosis Stigma Scale: Community-felt Stigma\(^{43}\)               | Amharic and Wolaitigna                                                   | 483 | Adequate  | EFA: 4-factor solution (\(-\)) | 483 Very good          | Cronbach's alpha: 0.85 (\(-\)) |                    |
| Podoconiosis Stigma Scale: Community-enacted Stigma\(^{43}\)            | Amharic and Wolaitigna                                                   | 483 | Adequate  | EFA: 2-factor solution (\(-\)) | 483 Very good          | Cronbach's alpha: 0.91 (\(-\)) |                    |
| SARI Stigma Scale (SSS)\(^{44}\)                                        | Bahasa Indonesia                                                        | 392 | Adequate  | EFA: 4-factor solution (\(?\)) | 392 Very good          | Cronbach's alpha: 0.88 (\(+\)) |                    |
| Satisfaction With Appearance Scale – Perceived Social Impact and Social Discomfort subscales (SWAP-PSI/SD)\(^{13}\) | English                                                                 | 165 | Adequate  | EFA: 4-factor solution, PSI/SD scales confirmed (\(-\)) | 165 Inadequate         | Cronbach's alpha total: 0.87 |                    |
| Adapted Satisfaction With Appearance Scale – Perceived Social Impact subscale (SWAP-PSI)\(^{13}\) | English                                                                 | 254 | Adequate  | EFA: 2-factor solution, PSI scale confirmed (\(-\)) | 254 Very good          | Cronbach's alpha PSI: 0.89 (\(+\)) |                    |
| Social Comfort Questionnaire (SCQ)\(^{42}\)                             | English                                                                 | 361 | Adequate  | EFA: 1-factor scale (\(?\)) | 361 Very good          | Cronbach's alpha: 0.91 (\(-\)) |                    |
| Social Comfort Questionnaire (SCQ)\(^{42}\)                             | Portuguese                                                              | 240 | Very good | EFA: 1-factor scale (\(-\)), after omission of 2 items (\(-\)) | 240 Very good          | Cronbach's alpha: 0.74 (\(-\)) |                    |
| Social Comfort Questionnaire (SCQ)\(^{42}\)                             | Portuguese                                                              | 369 | Very good | EFA: 1-factor scale (\(-\)) | 369 Very good          | Cronbach's alpha: 0.78 (\(+\)) |                    |
| Social Distance Scale (SDS)\(^{13}\)                                     | German                                                                  | 146 | Very good | EFA: 1-factor scale (\(-\)) | 146 Very good          | Cronbach's alpha: 0.85 (\(+\)) |                    |
| Questionnaire on Experience of Skin Complaints (QES)\(^{57}\)           | Indonesian                                                              | 259 | Adequate  | EFA: 1-factor solution (\(?\)) | 259 Very good          | Cronbach's alpha: 0.87 (\(-\)) |                    |
| Questionnaire on Experience of Skin Complaints (QES)\(^{57}\)           | German                                                                  | 385 | Adequate  | EFA: 6-factor solution (\(?\)) | 385 Very good          | Cronbach's alpha: 0.86 (\(+\)) |                    |
| Questionnaire on Experience of Skin Complaints-Short Form (QES-SF)\(^{43}\) | German                                                                  | 463 | Adequate  | EFA: 4-factor solution (\(-\)) | 463 Very good          | Cronbach's alpha F1: 0.87 (\(+\)) |                    |
| Questionnaire on Experience of Skin Complaints-Short Form (QES-SF)\(^{43}\) | German                                                                  | 1,010 | Very good | Initial EFA: 4-factor solution (\(-\)), SBM: 5-factor solution (\(-\)) | 1,010 Inadequate       | Based on theory (\(-\)) |                    |

CFA, confirmatory factor analysis; EFA, exploratory factor analysis; EMIC, Explanatory Model Interview Catalogue; ICC, intraclass coefficient.

1 Responses between parents/caregivers and children.
2 Prolonged retest period due to ‘misunderstanding’ in study.
| PROM (ref) | Language | Hypothesis testing | Responsiveness |
|-----------|-----------|--------------------|----------------|
| DISABKIDS Atopic Dermatitis Module – Stigma subscale | English, German, French, Greek, Dutch, Swedish | - | - |
| DISABKIDS Atopic Dermatitis Module – Stigma subscale | Portuguese | 52 | Very good |
| EMIC Community Stigma Scale (EMIC-CSS) | Indonesian | 259 | Very Good |
| EMIC Community Stigma Scale (EMIC-CSS) | Tamil and Bengali | - | - |
| EMIC Stigma Scale (EMIC-SS) | Tamil and Bengali | 806 | Very Good |
| EMIC Stigma Scale (EMIC-SS) | Portuguese | 180 | Very Good |
| Feelings of Stigmatization Scale (FSQ) | English | 100 | Doubtful |
| Feelings of Stigmatization Questionnaire (FSQ) | Arabic | 39 | Very good |

- Moderate-to-strong correlations between scores and rated severity of the disease for discriminant validity.
- Convergent validity with correlations > 0.30 (2 out of 2, +)
- Positive correlation between the EMIC-CSS total score and the SDS total score (r = 0.41) (1 out of 1, +)
- Leprosy-affected persons in the control group scored higher than the community rehabilitation group on the Participation Scale, ISMI and EMIC, and lower on the GSE (p<0.05)
- Differences between leprosy-affected and non-affected respondents for the Participation Scale (p<0.001), the General Self-Esteem Scale (p<0.001), (6 out of 6, +)
- Total scores and factors: moderate positive monotonic correlations with depression and restriction in social participation, and negative monotonic correlations with self-esteem, confirming the convergent validity for the one and two-dimensional models
- Moderate positive correlations with depression and P-Scale (5 out of 5, +)
- Variables that proved to be predictors for feeling the effect of stigmatization most effectively: age of onset, extent of bleeding, work status, methotrexate treatment, rejection experience, duration, years of education, clinic sample (5 out of 6, ?)
- Correlation between the total score of 6-item Stigmatization Scale and DLOI (p = 0.54, p < 0.001)
- Correlation between 6-item Stigmatization Scale and Feelings of Stigmatization Questionnaire (p = -0.42, p = 0.007) (2 out of 2, +)
| PROM (ref) | Language                      | Hypothesis testing                                                                 | Responsiveness                                                                 |
|-----------|-------------------------------|----------------------------------------------------------------------------------|---------------------------------------------------------------------------------|
| Hairdex Stigma subscale | German | N 75 Meth qual Very good - correlations between the Hairdex and relevant subscales of the Dermatology Quality of Life & Nottingham Health Profile (2 out of 2, +) | N 75 Meth qual Results (rating)                                                                                           |
| Internalized Stigma of Mental Illness (ISMI) | Tamil and Bengali | N 806 Meth qual Very good - significant difference in level of ‘internalized stigma’ between community-based rehabilitation and control group in the group of leprosy-affected persons with visible signs p (median 2.27 and 2.56, respectively; p = 0.002) | N 806 Meth qual Results (rating)                                                                                           |
| Impact of Chronic Skin Disease on Daily Life (ISDL) Stigma subscale | Dutch | N 301 Meth qual Very good - moderate (0.30–0.50) to relatively high (>0.50) correlations between ISDL subscales and disease activity, disease-related quality of life, anxiety, depression and the personality characteristic of neuroticism (4 out of 6, +) | N 301 Meth qual Results (rating)                                                                                           |
| Impact of Chronic Skin Disease on Daily Life (ISDL) Stigma sub-scale/6-item Stigmatization Scale | Arabic | N 39 Meth qual Doubtful - correlation between the total score of 6-item Stigmatization Scale and DLQI (p = 0.54, p < 0.001) | N 39 Meth qual Results (rating)                                                                                           |
| Leprosy Internalised Stigma Scale (LISS) | Bengali | N 416 Meth qual Very good - Moderate positive correlation with P-scale (r = 0.51, p = 0.00), weak negative correlation with quality of life (r = 0.36, p = 0.00) (2 out of 2, +) | N 416 Meth qual Results (rating)                                                                                           |
| OnyCOE-t questionnaires – Stigma subscale | English | N 504 Meth qual Very good - Strong correlations between items measuring toenail symptom frequency, and bothersomeness - All problem scales and items – Physical Activities, Physical Appearance and Overall Problem – moderately to highly correlated. - highly correlated with constructs of embarrassment about appearance and social stigma (5 out of 5, +) | N 504 Meth qual Results (rating)                                                                                           |
| Participation Scale (P-Scale) | Hindi, Bengali, Telugu and Tamil, Portuguese, Nepalese | N 504 Meth qual Very good - Positive correlations with expert scores, other impairment scores and VAS rating of general life satisfaction (3 out of 3, +) | N 504 Meth qual Results (rating)                                                                                           |
| PROM (ref) | Language                | Hypothesis testing                                                                 | Responsiveness |
|-----------|-------------------------|-----------------------------------------------------------------------------------|----------------|
|           |                         | N | Meth qual | Results (rating) | N | Meth qual | Results (rating) |
| Participation Scale (P-Scale) | Tamil and Bengali | 806 | Very good | - differences between participants with and without visible signs of leprosy (median 17 and 5, respectively; p = 0.0001) | - significant differences in level of participation between those in the community rehabilitation group and those in the control group | - Differentiation between people with visible and non-visible signs, positive correlations to P-scale, ISMI | 3 out of 3, ^1 |
| Participation Scale (P-Scale) | Twi and French          | 143 | Very good | - P-scale scores of former patients with BU with visible deformities were significantly (P= .023) higher than those without visible deformities | - P-scale scores of former patients with BU with joint involvement were nearly significantly (P= .056) higher than those without joint involvement | - P-scale scores of former patients with BU that changed occupation were (not significantly) higher compared with those that continued the same occupation (P = .809) | - Spearman’s rank correlation of 0.67 between the BUFLS and P-scale scores | - Spearman’s rank correlation of 0.53 between the EMIC and the P-scale | - Spearman’s rank correlation of 0.80 between the P-scale sum scores of former BU patients and relatives | 4 out of 6, ^1 |
| Participation scale (P-Scale) | Various                 | - | - | - | - | - | - |
| Participation Scale short (P-Scale Short) | Various                 | - | - | - | - | - | - |
| Perceived Stigmatization Questionnaire (PSQ) | English                 | 361 | Very Good | - Intercorrelations with SCQ negative | - negative correlations with Body-Esteem Scale, Mood and Feelings Questionnaire, Interpersonal Support Evaluation List | - strong correlations with the BDI (depression), RSES (self-esteem), BSHS-R (affect/body image and interpersonal relationships) | (3 out of 4, ^1) |
| Perceived Stigmatization Questionnaire (PSQ) | Portuguese               | 240 | Very Good | - | - | - | - |
Table 4  Continued

| PROM (ref) | Language | Hypothesis testing                                                                 | Responsiveness |
|------------|----------|-----------------------------------------------------------------------------------|----------------|
|            |          | N Meth qual Results (rating)                                                     | N Meth qual Results (rating) |
| Perceived Stigmatization Questionnaire (PSQ) | Portuguese | 369 Very good Correlations between first-order factors of the PSQ and SCQ from .459 to -.791 (2 out of 2, +) |           |
| Perceived Stigmatization Questionnaire (PSQ) | German | 146 Very good Significant correlations between the PSQ factors and the SCQ factor - Negative correlations with social support, burn related quality of life, positive correlation to depression scores (4 out of 4, +) |           |
| Podoconiosis Stigma Scale: Patients-enacted Stigma | Amharic and Wolaitigna | 150 Very good Significant correlation between the felt and enacted stigma scales among patients (Spearman's r = 0.892; p < 0.001) (1 out of 1, +) |           |
| Podoconiosis Stigma Scale: Community-felt Stigma | Amharic and Wolaitigna | 150 Very good Significant correlation between the felt and enacted stigma scales within the community (Spearman's r = 0.794; p < 0.001) (1 out of 1, +) |           |
| Podoconiosis Stigma Scale: Community-enacted Stigma | Amharic and Wolaitigna | 483 Very good Significant correlation between the felt and enacted stigma scales within the community (Spearman's r = 0.794; p < 0.001) (1 out of 1, +) |           |
| Podoconiosis Stigma Scale: Patients-enacted Stigma | Amharic and Wolaitigna | 483 Very good Significant correlation between the felt and enacted stigma scales among patients (Spearman's r = 0.892; p < 0.001) - modest correlation between items (1 out of 1, +) |           |
| SARI Stigma Scale (SSS) | Bahasa Indonesia | 392 Very good Moderately positive correlation (r = 0.46, P < 0.0001) between the total SARI score and the P-scale - weak negative correlation (r = -20.37, p<0.0001) between the total score of the new scale and the WHOQOL (2 out of 2, +) |           |
| Satisfaction With Appearance Scale – Perceived Social Impact and Social Discomfort subscales (SWAP-PSI/SD) | English | 165 Inadequate Correlation with PASTAS (r = .63, p < .01), BDI (r = .31, p < .01), DTS (r = .27, p < .01), BAI (r = .26, p < .01), SF-36 Social Functioning (r = -.40, p < .01), SF-36 Vitality (r = -.42, p < .01) and SF-36 Mental Health (r = -.43, p < .01) - Total score correlates with body image, depression, anxiety in expected directions (8 out of 10, +) |           |
| PROM (ref) | Language | N | Meth qual | Results (rating) | Responsiveness |
|-----------|----------|---|-----------|-----------------|----------------|
| Adapted Satisfaction With Appearance Scale - Perceived Social Impact sub-scale (SWAP-PSI) | English | 254 | Very good | - Moderate correlations with the HAQ (ranging from 0.33 to 0.43) and with the BDI (ranging from 0.40 to 0.57) - lowest correlations with pain (ranging from 0.23 to 0.33) - Positive correlation with severity, body image avoidance (2 out of 4, -) | |
| Social Comfort Questionnaire (SCQ) | English | 361 | Very good | - Intercorrelations with PSQ - negative correlations with Body-Esteem Scale, Mood and Feelings Questionnaire, Interpersonal Support Evaluation List (4 out of 4, +) | |
| Social Comfort Questionnaire (SCQ) | Portuguese | 240 | Very good | - strong negative correlation with depression (BDI) - strong positive correlations with affect/ body image (BSHS-R), interpersonal relationships (BSHS-R) and self-esteem (RSES) (all p < 0.001) (4 out of 4, +) | |
| Social Comfort Questionnaire (SCQ) | Portuguese | 369 | Very good | - Correlations between first-order factors of the PSQ and SCQ ranged from -0.459 to -0.791 (1 out of 1, +) | |
| Social Comfort Questionnaire (SCQ) | German | 146 | Very good | - Positive correlation with perceived social support, burn-related quality of life, negative correlation with depression scores (2 out of 2, +) | |
| Social Distance Scale (SDS) | Indonesian | 259 | Very good | - moderately positive correlation between the EMIC-CSS total score and the SDS total score (r = 0.41) (1 out of 1, +) | |
| Questionnaire on Experience of Skin Complaints (QES) | German | 385 | Very good | - Affected sensible regions (genitals, abdomen) are associated with higher QES scores (1 out of 1, +) | |
| Questionnaire on Experience of Skin Complaints (QES) – 34 items | German | 374 | Very good | - only the ‘pathologic’ scales of the QES (Self-esteem, Retreat, Rejection and Concealment) show significant interrelations with the dimension ‘Rumination’ of the TSK - Affected sensible regions (genitals, abdomen) are associated with higher QES scores (1 out of 3, -) | |
that report a gap in evidence concerning socio-demographic and disease characteristics, as well as a strong focus of research on self-stigma and a lack of studies focusing on enacted stigma.\textsuperscript{16}

However, this circumstance limits knowledge about causes and impact of stigma – particularly regarding enacted stigma – in visible skin diseases in general and in individual skin diseases, and patients of different age groups. As skin diseases are the cause of substantial non-fatal disability worldwide, also in poorer areas of the world, the psychosocial consequences will need to be focused on in order to reduce the burden of disease.\textsuperscript{63}

Covering the first main result, instruments on Hansen’s disease most often originate in developing countries, where the disease is still prevalent and a public health concern. On the contrary, instruments on the stigma of atopic dermatitis and psoriasis are mainly developed in Western countries, reflecting their importance in those healthcare settings. With changes in the healthcare system in developing countries as well, cultural adaption of instruments developed in other regions of the world will be needed. It has been documented that stigma is indeed culturally sensitive – while some aspects are similar across cultures and ethnicities, others are specific to certain populations.\textsuperscript{64}

As a second main result, we observed that instruments to assess stigmatization in children and adolescents are lacking or have not been used in validation studies. This is of importance as some visible skin diseases, such as atopic dermatitis, have an onset early on in life and affect the lives of children and adolescents, and it is known that stigmatization in the general public prevails.\textsuperscript{65} Instruments used in adult populations may be suitable for adolescents as well, but will need validation in these populations. Investigations on stigma in other fields, such as mental health, report the same gap in research.\textsuperscript{66}

Lastly, we observed that instruments mainly exist to measure felt stigma in those affected by a visible skin disease. While one could argue that the felt reality of those affected is the most important part of stigma, the lack of studies on enacted stigma makes the big picture incomplete. Additionally, this part is needed to determine the nature of stigmatization and its consequences in visible skin diseases. Felt stigma with no correlate in enacted stigma may then represent a facet of the mental health burden of the disease but not its public devaluation. Obviously, there have been attempts to measure enacted stigma across several skin diseases, such as psoriasis,\textsuperscript{65,67} but validated instruments are lacking. Validated instruments are also lacking when thinking about measuring effects of intervention studies. In Germany, for instance, the German Ministry of Health initiated the development of an intervention to reduce public stigma in visible skin diseases,\textsuperscript{68} and the lack of validated PROMs was a challenge of the study team.

**Strengths and limitations**

This is the first review to follow PRISMA and COSMIN guidelines to report measures of stigmatization in patients with visible skin diseases.
Table 5 Summary of findings

| PROM | Summary or pooled result | Overall rating | Quality of evidence | Recommendation |
|------|--------------------------|----------------|---------------------|----------------|
| DISABKIDS Atopic Dermatitis Module – Stigma subscale | | | | B |
| Content validity | ± | Only 4 items that are randomly assigned to the stigma subscale, thorough development process, but not aimed at finding a scale for stigma | | |
| Structural validity | Stigma subscale in EFA reported, criteria for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Moderate: One adequate study | |
| Internal consistency | 0.71-0.81 | Sufficient | High | |
| Cross-cultural validity | No information available | No information available | No information available | |
| Reliability | 0.76-0.84 | Sufficient | High | |
| Hypothesis testing | 12 out of 12 hypotheses confirmed | Sufficient | High | |
| Responsiveness | No information available | No information available | No information available | |
| EMIC Community Stigma Scale (EMIC-CSS) | | | | A |
| Content validity | + | Clear stigma-oriented development on perceived stigma in the community, clear aim and scope | | |
| Structural validity | EFA reports two highly correlated factors, supports higher-order factor | Sufficient | Moderate: One adequate study | |
| Internal consistency | 0.83-0.88 | Sufficient | High | |
| Cross-cultural validity | No information available | No information available | No information available | |
| Reliability | 0.70-0.84 | Sufficient | High | |
| Hypothesis testing | 1 out of 1 hypothesis confirmed | Sufficient | High | |
| Responsiveness | No information available | No information available | No information available | |
| EMIC Stigma Scale (EMIC-SS) | | | | A |
| Content validity | + | Clear stigma-oriented development on perceived stigma, clear aim and scope | | |
| Structural validity | 2-factor scale reported | Sufficient | High | |
| Internal consistency | 0.78-0.88 total scale, subscales 0.63-0.71 | Sufficient | High | |
| Cross-cultural validity | No information available | No information available | No information available | |
| Reliability | 0.70-0.75 total scale, subscales 0.64-0.70 | Sufficient | High | |
| Hypothesis testing | 11 out of 11 hypotheses confirmed | Sufficient | High | |
| Responsiveness | No information available | No information available | No information available | |
| Feelings of Stigmatization (FSQ) | | | | A |
| Content validity | + | Clear and theoretical scale development | | |
| Structural validity | 3-factor solution reported in high quality study | Sufficient | High | |
| PROM                                      | Summary or pooled result | Overall rating | Quality of evidence | Recommendation |
|-------------------------------------------|--------------------------|----------------|---------------------|----------------|
| Internal consistency                      | Consistently above 0.70  | Sufficient     | High                |                |
| Cross-cultural validity                   | No information available | No information available | No information available |                |
| Reliability                               | 0.92                     | Sufficient     | High                |                |
| Hypothesis testing                        | 7 out of 8 hypotheses confirmed | Sufficient     | High                |                |
| Responsiveness                            | No information available | No information available | No information available |                |
| Hairdex Stigma subscale                   |                          |                |                     | B              |
| Content validity                          | +                        | Subscale clearly aimed at stigma, social rejection/fear of social rejection |                |                |
| Structural validity                       | Criteria for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Moderate: one adequate study |                |
| Internal consistency                      | 0.68                     | Insufficient   | High                |                |
| Cross-cultural validity                   | No information available | No information available | No information available |                |
| Reliability                               | No information available | No information available | No information available |                |
| Hypothesis testing                        | 2 out of 2 hypotheses confirmed | Sufficient     | High                |                |
| Responsiveness                            | No information available | No information available | No information available |                |
| Internalized Stigma of Mental Illness (ISMI) |                          |                |                     | B              |
| Content validity                          | +                        | Clearly developed, all theoretical constructs included |                |                |
| Structural validity                       | Criteria for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Low: no high-quality study available |                |
| Internal consistency                      | 0.84-0.88                | Sufficient     | High                |                |
| Cross-cultural validity                   | No information available | No information available | No information available |                |
| Reliability                               | 0.62                     | Insufficient   | High                |                |
| Hypothesis testing                        | 2 out of 2 hypotheses confirmed | Sufficient     | High                |                |
| Responsiveness                            | No information available | No information available | No information available |                |
| Impact of Chronic Skin Disease on Daily Life (ISDL) Stigma subscale |                          |                |                     | B              |
| Content validity                          | +                        | Subscale clearly aimed and developed for stigmatization |                |                |
| Structural validity                       | Criteria for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Low: no high-quality study available |                |
| Internal consistency                      | 0.84-0.88                | Sufficient     | High                |                |
| Cross-cultural validity                   | No information available | No information available | No information available |                |
| Reliability                               | 0.92                     | Sufficient     | High                |                |
| Hypothesis testing                        | 5 out of 7 hypotheses confirmed | Sufficient     | High                |                |
| Responsiveness                            | Sign, positive changes after intervention | Sufficient     | High                |                |
| Leprosy Internalised Stigma Scale (LISS)  |                          |                |                     | B              |
| Content validity                          | +                        | Clear scale development from literature and experts |                |                |
### Table 5  
**Continued**

| PROM | Summary or pooled result | Overall rating | Quality of evidence | Recommendation |
|------|--------------------------|----------------|---------------------|----------------|
| **Structural validity** | Criterias for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Moderate: one adequate study | |
| **Internal consistency** | 0.96 | Sufficient | High | |
| **Cross-cultural validity** | No information available | No information available | No information available | |
| **Reliability** | No information available | No information available | No information available | |
| **Hypothesis testing** | 2 out of 2 hypotheses confirmed | Sufficient | High | |
| **Responsiveness** | No information available | No information available | No information available | |
| **OnyCOE-t™ questionnaire – Stigma subscale** | | | | |
| **Content validity** | ± | Unclear, questionnaire cannot be retrieved | | |
| **Structural validity** | Criterias for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Low: no high-quality study available | |
| **Internal consistency** | 0.84-0.91 | Sufficient | High | |
| **Cross-cultural validity** | No information available | No information available | No information available | |
| **Reliability** | No information available | No information available | No information available | |
| **Hypothesis testing** | 5 out of 5 hypotheses confirmed | Sufficient | High | |
| **Responsiveness** | Sign. positive changes after intervention | Sufficient | High | |
| **Participation Scale (P-Scale)** | | | | |
| **Content validity** | + | Clear development, construct clearly defined | | |
| **Structural validity** | 2 factor solution | Sufficient | High | |
| **Internal consistency** | 0.88-0.93 | Sufficient | High | |
| **Cross-cultural validity** | No differences found | Sufficient | High | |
| **Reliability** | No information available | No information available | No information available | |
| **Hypothesis testing** | 7 out of 9 hypotheses confirmed | Sufficient | High | |
| **Responsiveness** | No information available | No information available | No information available | |
| **Participation Scale Short (P-Scale Short)** | | | | |
| **Content validity** | + | Clear development, construct clearly defined | | |
| **Structural validity** | 2-factor solution | Sufficient | High | |
| **Internal consistency** | 0.83-0.91 | Sufficient | High | |
| **Cross-cultural validity** | No information available | No information available | No information available | |
| **Reliability** | No information available | No information available | No information available | |
| **Hypothesis testing** | No information available | No information available | No information available | |
| **Responsiveness** | No information available | No information available | No information available | |
| **Perceived Stigmatization Questionnaire (PSQ)** | | | | |
| **Content validity** | + | Clear development, construct clearly defined | | |

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| PROM | Summary or pooled result | Overall rating | Quality of evidence | Recommendation |
|------|--------------------------|----------------|---------------------|----------------|
| Structural validity | 3-factor solution | Sufficient | High |
| Internal consistency | 0.65-0.90 | Sufficient | High |
| Cross-cultural validity | No information available | No information available | No information available |
| Reliability | 0.79-0.87 | Sufficient | High |
| Hypothesis testing | 13 of 14 hypotheses confirmed | Sufficient | High |
| Responsiveness | No information available | No information available | No information available |
| Podoconiosis Stigma Scale: felt and enacted stigma patients<sup>43</sup> |  |  |  | A |
| Content validity |  | Comprehensive development, items from literature, Delphi/expert groups, etc. |
| Structural validity | 1-factor solution | Sufficient | Moderate: one adequate study |
| Internal consistency | 0.94-0.96 | Sufficient | High |
| Cross-cultural validity | No information available | No information available | No information available |
| Reliability | No information available | No information available | No information available |
| Hypothesis testing | 1 of 1 hypothesis confirmed | Sufficient | High |
| Responsiveness | No information available | No information available | No information available |
| Podoconiosis Stigma Scale: felt and enacted stigma community<sup>43</sup> |  |  |  | A |
| Content validity |  | Comprehensive development, items from literature, Delphi/expert groups, etc. |
| Structural validity | 4- and 2-factor solutions | Sufficient | Moderate: one adequate study |
| Internal consistency | 0.85-0.91 | Sufficient | High |
| Cross-cultural validity | No information available | No information available | No information available |
| Reliability | No information available | No information available | No information available |
| Hypothesis testing | 1 of 1 hypothesis confirmed | Sufficient | High |
| Responsiveness | No information available | No information available | No information available |
| SARI Stigma Scale (SSS)<sup>44</sup> |  |  |  | B |
| Content validity |  | Based on Berger HIV stigma scale, thorough development |
| Structural validity | Criteria for ‘at least low evidence for sufficient structural validity’ not met | Indeterminate | Moderate: one adequate study |
| Internal consistency | 0.79-0.88 | Sufficient | High |
| Cross-cultural validity | No information available | No information available | No information available |
| Reliability | 0.54-0.75 | Insufficient | High |
| Hypothesis testing | 2 out of 2 hypotheses confirmed | Sufficient | High |
| Responsiveness | No information available | No information available | No information available |
| Satisfaction With Appearance Scale – Perceived Social Impact and Social Discomfort subscales (SWAP-PSI/SD)<sup>45</sup> |  |  |  | A |
Table 5  Continued

| PROM                                                                 | Summary or pooled result | Overall rating | Quality of evidence | Recommendation |
|----------------------------------------------------------------------|--------------------------|----------------|---------------------|----------------|
| **Content validity**                                                 |                          |                |                     |                |
| For the construct measured, content validity seems given             |                          |                |                     |                |
| **Structural validity**                                              | 4-factor solution        | Sufficient     | Moderate: one adequate study |                |
| **Internal consistency**                                             | 0.87                     | Indeterminate  | Low (only full scale reported) |                |
| Cross-cultural validity                                              | No information available | No information available | No information available |                |
| Reliability                                                          | 0.59                     | Indeterminate  | Moderate: one adequate study |                |
| Hypothesis testing                                                   | 8 out of 10 hypotheses confirmed | Sufficient | Low (inadequate hypothesis testing) |                |
| Responsiveness                                                       | No information available | No information available | No information available |                |
| Adapted Satisfaction With Appearance Social Impact subscale (ASWAP-PSI) |                        |                |                     |                |
| Content validity                                                     |                          |                |                     |                |
| For the construct measured, content validity seems given             |                          |                |                     |                |
| **Structural validity**                                              | 2-factor solution        | Sufficient     | Moderate: one adequate study |                |
| **Internal consistency**                                             | 0.89                     | Sufficient     | High                |                |
| Cross-cultural validity                                              | No information available | No information available | No information available |                |
| Reliability                                                          | 0.72                     | Sufficient     | High                |                |
| Hypothesis testing                                                   | 2 out of 4 hypotheses confirmed | Indeterminable | High                |                |
| Responsiveness                                                       | No information available | No information available | No information available |                |
| Social Comfort Questionnaire (SCQ)                                   |                          |                |                     |                |
| Content validity                                                     | +                        |                |                     |                |
| Clear development, construct clearly defined                          |                          |                |                     |                |
| **Structural validity**                                              | 1-factor solution        | Sufficient     | High (model fits are not always ideal, but one factor solution is consistent) |                |
| **Internal consistency**                                             | 0.74-0.91                | Sufficient     | High                |                |
| Cross-cultural validity                                              | No information available | No information available | No information available |                |
| Reliability                                                          | 0.82                     | Sufficient     | High                |                |
| Hypothesis testing                                                   | 11 out of 11 hypotheses confirmed | Sufficient | High                |                |
| Responsiveness                                                       | No information available | No information available | No information available |                |
| Social Distance Scale                                               |                          |                |                     |                |
| **Content validity**                                                 | +                        |                |                     |                |
| Long established instrument, clearly defined                          |                          |                |                     |                |
| **Structural validity**                                              | 1-factor solution        | Sufficient     | Indeterminable: one adequate study, model fits not reported |                |
| **Internal consistency**                                             | 0.87                     | Sufficient     | High                |                |
| Cross-cultural validity                                              | No information available | No information available | No information available |                |
| Reliability                                                          | 0.75                     | Sufficient     | High                |                |
| Hypothesis testing                                                   | 1 out of 1 hypothesis confirmed | Sufficient | High                |                |
| Responsiveness                                                       | No information available | No information available | No information available |                |
| Questionnaire on Experience of Skin Complaints (QES)                 |                          |                |                     |                |
| **Content validity**                                                 | +                        |                |                     |                |
| Long established instrument, clearly defined                          |                          |                |                     |                |
| **Structural validity**                                              | 1-factor solution        | Indeterminable | Moderate: one adequate study, model fits not reported |                |
| **Internal consistency**                                             | 0.87                     | Sufficient     | High                |                |
| Cross-cultural validity                                              | No information available | No information available | No information available |                |
| Reliability                                                          | 0.75                     | Sufficient     | High                |                |
| Hypothesis testing                                                   | 1 out of 1 hypothesis confirmed | Sufficient | High                |                |
| Responsiveness                                                       | No information available | No information available | No information available |                |
skin diseases. Its strengths can be found in its rigorous methodology and clear reporting. There are some limitations to report as well: firstly, language results had to be limited to English and German. This led to the exclusion of two studies and instruments that were only available in Polish. Furthermore, the definition of stigma was difficult to obey. For example, the Participation Scales could also be considered to reflect consequences of stigmatization, rather than felt stigma itself. However, in the search of reference lists, it became clear that most authors have subsumed these instruments under stigma, which is why we decided to follow this suggestion. Lastly, research on self-constructed instruments can lead to new validated instruments but were not included in the review at this point. Numerous studies emerged during the past few years, making updates of this review necessary.

To sum up, we were able to identify several validated instruments that can be recommended for use. Other instruments require more research but fulfil basic requirements for recommendation already at this point. Future research will need to focus on assessing stigma across different visible skin diseases, in children and adolescents, and also incorporating the views of the general public. By assessing stigmatization with instruments of psychometric validity and reliability, efforts to reduce public and self-stigmatization can be measured and comparability of results increase. As proposed, interventions to reduce stigmatization not only in the general public but also in healthcare professionals are needed. In this review, we find instruments that ensure a methodologically sound determination of the success of such interventions.

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Author contributions
CLS, NW, RS and MA contributed to conception and design. CLS, NW, PR and JT worked on the acquisition of data. All authors discussed, analysed and interpreted the data. CLS and NW drafted the article. PR, JT, RS and MA revised it critically for important intellectual content. All authors have approved the final version to be published.

Data Availability Statement
Data sharing is not applicable to this article as no data sets were generated or analysed during the current study.

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Table 5 Continued

| PROM | Summary or pooled result | Overall rating | Quality of evidence | Recommendation |
|------|--------------------------|----------------|---------------------|----------------|
| Content validity | + | Clearly aimed at stigma, measuring different facets | | |
| Structural validity | 6-factor solution | Indeterminable | Moderate: one adequate study, model fits not reported | |
| Internal consistency | 0.68-0.87 | Sufficient | High | |
| Cross-cultural validity | No information available | No information available | No information available | |
| Reliability | No information available | No information available | No information available | |
| Hypothesis testing | 2 out of 4 hypotheses confirmed | Indeterminable | High | |
| Responsiveness | No information available | No information available | No information available | |

| Questionnaire on Experience of Skin Complaints-Short Form (QES-SF)⁴⁸ | | | | |
| Content validity | + | Clearly aimed at stigma, measuring different facets | | |
| Structural validity | 5-factor solution | Sufficient | High (information from moderate-quality study excluded) | |
| Internal consistency | 0.72-0.87 | Sufficient | High | |
| Cross-cultural validity | No information available | No information available | No information available | |
| Reliability | No information available | No information available | No information available | |
| Hypothesis testing | 3 out of 3 hypotheses confirmed | Sufficient | High | |
| Responsiveness | Sign. positive changes after intervention | Sufficient | Sign. positive changes after intervention | |
Assessment of stigma related to visible skin diseases

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