



# BMJ Open Systematic review of psychosocial needs assessment tools for caregivers of paediatric patients with dermatological conditions

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## ABSTRACT

**Objective** To identify validated dermatology-specific and disease-specific psychosocial needs assessment tools for caregivers of paediatric patients with dermatological conditions. A secondary objective was to assess the adequacy of their measurement properties.

**Design** Systematic review.

**Data sources** EMBASE, PsycINFO, MEDLINE (in Ovid SP), Cochrane, Cumulative Index to Nursing and Allied Health EBSCO, U Search and Web of Science were searched (2000–5 October 2021). Grey literature, bibliographies, online databases of QoL tools and several trial registers were searched (2000–5 Oct 2021).

**Eligibility criteria** Eligible studies involved adult caregivers caring for a child (no age limit) with any form of any skin condition. Predetermined exclusion criteria, as per protocol, were applied to the search results.

**Data abstraction and synthesis** Title, abstract, full-text screening and data abstraction (standardised forms) were done independently in duplicate. Both's predefined methodological criteria assessed risk of bias. Narrative synthesis was used to present the findings.

**Results** 187 full-text articles were examined from a total of 8979 records. Most tools were generic QoL tools, relevant to spouse/partner or based on their child's perception of the disease or assessed patients' quality of life. Following quality appraisal, 26 articles were identified, and 11 tools (1 dermatology-specific and 10 disease-specific) were included. Information outcome domains were provided for each tool (study specific, questionnaire specific, adequacy of measurement properties and risk of bias). No literature was found pertaining to the use of these tools within healthcare settings and/or as e-tools.

**Discussion** With limited evidence supporting the quality of their methodological and measurement properties, this review will inform future dermatological Core Outcome Set development and improve evidence-based clinical decisions. Increasing demand on limited healthcare resources justifies the codevelopment of an accessible solution-focused psychosocial needs assessment e-tool to promote caregiver health outcomes.

**PROSPERO registration number** PROSPERO (CRD42019159956).

## Strengths and limitations of this study

- The first systematic review to provide a comprehensive overview of psychosocial assessment tools validated for use among dermatological caregivers of paediatric patients.
- This study was conducted with the involvement of a health and life subject-specific librarian and an international multidisciplinary expert group.
- The protocol was registered on the PROSPERO database (CRD42019159956), the COMET database and was conducted according to the recommendations from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 statement and ENTREQ statement.
- Adequacy of measurement properties was assessed using Both *et al's* criteria.
- Included articles were limited to being published in English between 2000 and 2021.

## INTRODUCTION

Paediatric dermatology is a unique speciality in that children with lifelong and life-limiting skin disorders are increasingly being cared for by caregivers at home,<sup>1</sup> which requires considerable cognitive, emotional and physical resources.<sup>2</sup> Skin disease is the fourth leading cause of global disease burden with associated prevalence, care requirements and costs comparable with other diseases, such as cardiovascular disease and diabetes.<sup>3–5</sup> Delayed identification of dermatological caregiver needs and provision of timely supports can seriously compromise the long-term psychosocial well-being of caregivers<sup>6–10</sup> and particularly undermine the care and treatment of paediatric patients affected by rare or chronic skin disease.<sup>11</sup> Caregivers of skin disease require similar systems of monitoring and integrated biopsychosocial support as other comparable chronic conditions.

The WHO directive,<sup>12</sup> recent international guidelines<sup>13 14</sup> and reports<sup>9 15 16</sup> emphasise the importance of identifying psychosocial needs

assessment tools for use among long-term caregivers, particularly self-referral models. Timely and appropriate identification of caregivers' unmet psychosocial needs has the potential to reduce caregiver strain and increase their ability to provide quality care within the home at reduced public health cost. Although a psychosocial needs assessment could be considered preventative in nature, by anticipating caregiver burnout and decreasing the need for emergency interventions, there is a lack of evidence regarding the use of caregiver assessment tools within healthcare settings. To date, no comprehensive review of psychosocial needs assessment tools validated for use among informal dermatological caregivers of paediatric patients has been conducted. With increasing competition for valuable healthcare resources and services, there is an urgent need to reconceptualise global burden within the construct of 'prevention is better than cure' by informing evidence-based decisions and promoting caregiver health outcomes within day-to-day clinical practice.

### Objectives

This review aimed to improve clinician access to existing dermatology-specific and disease-specific psychosocial needs assessment tools, validated for use among caregivers of paediatric patients with dermatological conditions. Additionally, this review assessed the adequacy of their measurement properties.

### METHODS

This review was conducted according to the recommendations from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement.<sup>17</sup> The ENTREQ statement was read and guided in reporting the synthesis of the findings.<sup>18</sup>

### Eligibility criteria

Studies that involved adult caregivers (age 18 years and over) caring for a child (no age limit) with any form of any skin condition were included. Predetermined exclusion criteria were adhered to (see protocol). Included articles were limited to being published in English between 01 January 2000 and 5 October 2021. This ensured that relevant assessment tools developed in the years before publication of the 2017 review<sup>19</sup> were included as that review had limited their search to one database and quality-of-life measures only, which contrasts with the measures recommended by the Cochrane Skin Centre of Evidence Based Dermatology.

### Information sources

MEDLINE, PsycINFO and Embase (OVID interface) and Cumulative Index to Nursing and Allied Health Literature (CINAHL) EBSCO were searched (1 January 2000–5 October 2021). Grey literature, bibliographies, online databases of QoL tools and several trial registers were also searched (1 January 2000–5 October 2021). A 'snowball' search was carried out to identify additional studies by

manually searching the reference lists of all publications eligible for full-text review. The PRISMA flow diagram (figure 1) includes the number of records identified from each source.

### Search strategy

One known relevant systematic review<sup>19</sup> was used as a starting point to identify records. A draft search strategy was developed by using candidate search terms that were identified in the titles, abstracts and subject indexing of that systematic review. The full search strategy development process is included in online supplemental file 1. This strategy was tailored to the specifications of each of the databases searched and developed in collaboration with a subject-specific librarian (JA) and expert group. Each tailored database search strategy is included in online supplemental file 2. All search terms/categories used to search within the supplementary sources are included in online supplemental file 3.

### Selection and data collection process

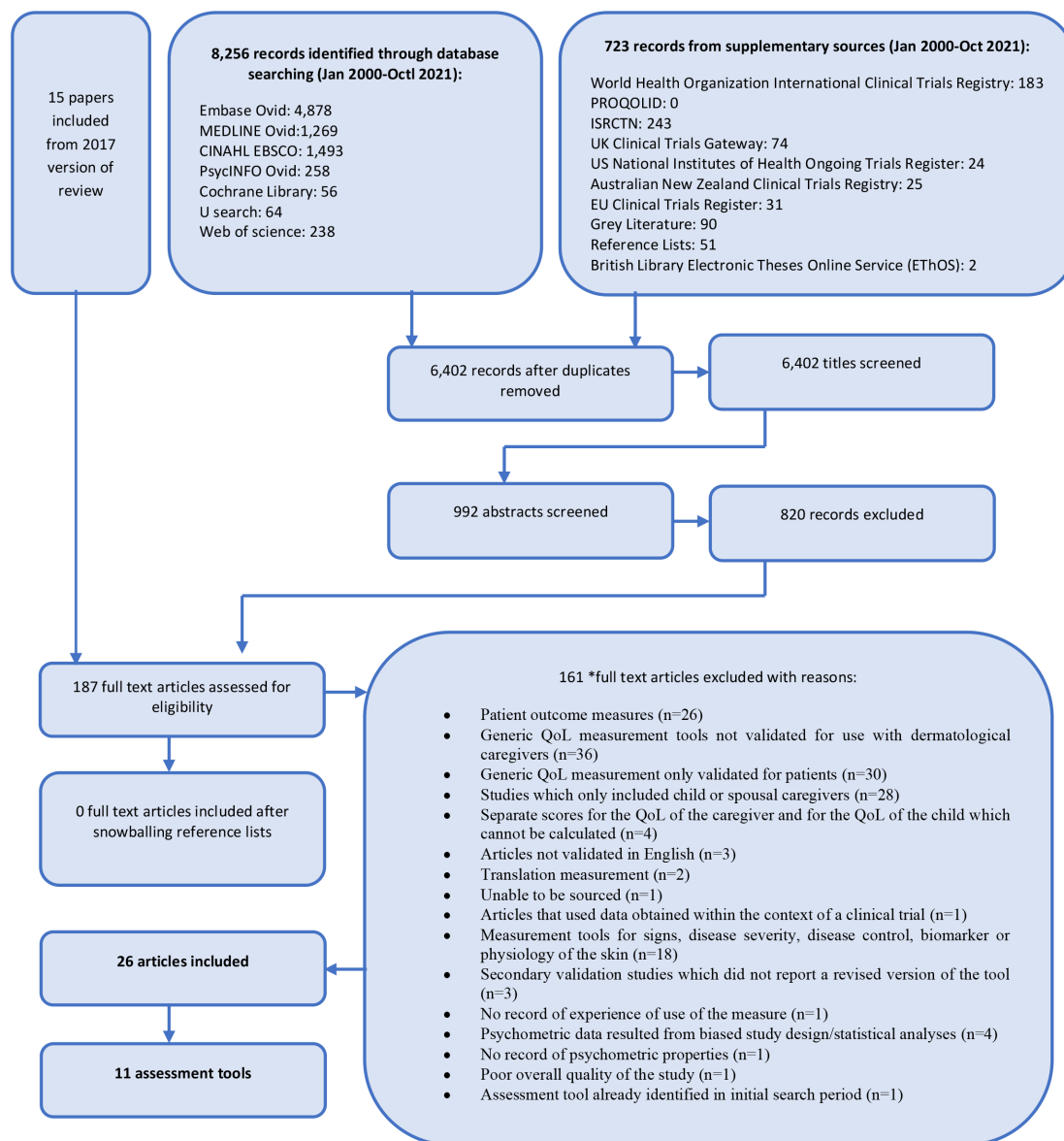
Title, abstract and full-text screening were conducted manually in duplicate (independently) by two reviewers (CW and GL). Extracted data from full-text articles was processed using three standardised extraction forms: (1) study-specific information included the name of the tool, country of origin, disease of affected patients, sample sizes used in each stage of its development and study setting; (2) questionnaire-specific information included the outcome domains, number of items and subscales, recall period, scoring system, respondent feedback and administration mode and time; (3) adequacy of measurement properties was evaluated using five methodological domains: validity, reliability, structure, interpretability and transferability. At the full-text screening stage, any discrepancies were resolved by discussion and, where necessary, the third author (MM) was consulted.

### Risk of bias assessment

Risk of bias in the included studies was assessed independently by two reviewers using Both *et al's*<sup>20</sup> criteria, made possible by the similarities between the studies. Each methodological domain and item were graded for risk of bias using predefined criteria. Any discrepancies were resolved by consensus discussions (CW and GL) and, where necessary, by deferment to the third author (MM). No overall risk of bias judgement that summarised across domains was given due to the wide variation in assessment across domains within each tool. To improve the robustness of the synthesis and facilitate replicability,<sup>21</sup> an overview of the domain definitions, items, effect measures, grades and criteria used in assessing the risk of bias is provided in online supplemental file 4.

### Synthesis methods

In line with synthesis guidelines,<sup>22</sup> a narrative approach was used to arrange the results into two categories: dermatology-specific and disease-specific tools psychosocial needs assessment tools. To ease identification of



**Figure 1** PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.; CINAHL, Cumulated Index to Nursing and Allied Health Literature; EBSCO, Elton B. Stephens Company; PsycINFO, Psychological Information Database; U Search, Ulster University Search; PROQOLID, Patient-Reported Outcome and Quality of Life Instruments Database; ISRCTN, International Standard Randomised Controlled Trials Number; UK, United Kingdom; US, United States; EU, European Union; QoL, Quality of Life.

variability between and within the included tools, results were also tabulated using the subheadings used in each of the three data extraction forms.

### Certainty assessment

The robust search strategy was validated in MEDLINE when it successfully identified the one known systematic review<sup>19</sup> as part of the search strategy development process (online supplemental file 1). Two authors (CW and GL) independently assessed the certainty of evidence by assessing risk of bias using a predefined checklist of criteria.<sup>20</sup>

### Ethics approval

Informed consent was obtained from all participating members of the expert group associated with the research project

### Patient and public involvement (PPI)

An international multidisciplinary expert group (n=15), including affected adults, clinical psychologists, clinical nurse specialists, consultant dermatologists, health policy advisors and caregivers, was established at the outset of the project (September 2017). Anonymity remains protected due to their ongoing involvement in another follow-on study. The Guidance for Reporting Involvement of Patients and the Public Short Form checklist was used to improve the reporting of PPI in our study.<sup>23</sup> PPI helped identify the research question, guide in terms of review design (search strategy, inclusion and exclusion criteria and data extraction subheadings) and improve the dissemination of findings (invitations to poster and orally



present at international dermatology and psychology conferences).

## RESULTS

This review identified 8979 records: 8256 records from database searching and 723 records from supplementary sources. After duplicates were removed ( $n=2577$ ), 6402 records were available. Of the 6402 titles screened, 992 abstracts were screened, and 187 full-text articles were assessed for eligibility. This included 15 records identified from the one known systematic review. Of the 187 full-text articles assessed for eligibility, 161 records were excluded for reasons that met the exclusion criteria (PRISMA flow diagram; figure 1). No full-text records were included after snowballing reference lists (48 screened).

To improve transparency, summaries of the records identified during the initial and updated searches, for both databases and supplementary sources, are included in online supplemental files 3 and 5. PRISMA flow diagrams are included for both the initial search (1 January 2000–1 April 2020) (online supplemental file 5 (figure 1)) and updated search periods (1 April 2020–5 October 2020) (online supplemental file 5 (figure 2)) and provide a breakdown of the number of records identified for each database and supplementary source. The two full-text articles, identified in the updated search, were both excluded when assessed for eligibility. One record<sup>24</sup> contained psychometric data resulting from a biased study design and statistical analysis ('validity was established in a limited range of subjects', 'the parents that responded to the survey were all mothers', 'single-institution cross-sectional study in Japan targeting parents of first-time patients less than 7 years old'). The other record<sup>25</sup> identified the Family Dermatology Life Quality Index (FDLQI), which was already identified in the initial search.

The majority of existing, validated dermatological assessment tools identified were generic quality of life (QoL) tools and/or assess the patients' QoL. Of those tools validated for use among caregivers, most were either relevant to spouse/partner or depend on the caregiver to complete but are based on their child's perception of the disease (figure 1). Very few needs assessment tools were validated for use among caregivers of paediatric patients affected with dermatological disease. In summary, a total of 11 assessment tools were identified from the 26 articles included in this review.<sup>26–36</sup> Ten disease-specific assessment tools were identified (The Psoriasis Family Index (PFI-15),<sup>26</sup> Family Pso,<sup>27</sup> Quality of life in Primary Caregivers of Children with Atopic Dermatitis (QPCAD),<sup>28</sup> Childhood Atopic Dermatitis Impact Scale (CADIS),<sup>29</sup> Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD),<sup>30</sup> Dermatitis Family Impact (DFI),<sup>31</sup> Parental Self-Efficacy with Eczema Care Index (PASECI),<sup>32</sup> CareGiver Oncology Quality of Life (CarGOQoL),<sup>33</sup> Epidermolysis Bullosa – Burden of Disease (EB-BoD)<sup>34</sup> and Family Burden of Ichthyosis (FBI)<sup>35</sup>) and one dermatology-specific

assessment tool was identified (FDLQ<sup>36</sup>). Table 1 provides a summary of study-specific information and includes the name of tool, country of origin, disease of affected patient, sample sizes and study setting. Table 2 summarises questionnaire-specific information under the subheadings outcome domains, subscales, number of items, recall period, scoring system and administration time. Table 3 provides an overview of the adequacy of the measurement properties of the included tools, including transferability, reliability, validity, structural and interpretability. Table 4 provides a graded risk of bias assessment (using the predefined criteria) of each methodological domain and item for each of the 11 tools.

### Disease-specific needs assessment tools

The Psoriasis Family Index (PFI-15)<sup>26</sup> is recommended for use alongside a dermatology-specific tool. As it is assessed on current time only, it does not rely on accurate recall. However, due to the small sample size, factor analysis could not be done, and there is a lack of comparison of PFI scores with other generic family QoL scales. In order to achieve its Cronbach's alpha value (0.86), it was necessary to delete five items. It has a weaker focus on the emotional aspects of living with affected members. Those accompanying patients to the primary care centre and inpatients were not included in the creation of the PFI, which restricts the generalisation of the quantitative findings.

The Family Pso<sup>27</sup> was created from interviews ( $n=95$ ) with psoriasis patients and their family members. Three experts (no caregiver involvement) decided the generation items for piloting and item reduction. Other limitations include that a small sample was used in its testing and were predominantly female partners of the interviewees. Its advantages include that the wording is more focused on emotional aspects of caregiving as opposed to HR-QoL.

Four tools were found that assess the impact of atopic dermatitis on the family. The QPCAD<sup>28</sup> has a 1-week recall and has been validated for use among primary caregivers of children with AD in the Japanese version only. Convergent validity requires further study, and only caregivers of mild and moderate patients from an urban area were included in the study.

The CADIS<sup>29</sup> is validated for use with both patients and parents of patients younger than 6 years. Rasch analysis reduced the tool to a 45-item version, which is responsive to clinical change in AD.

The Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD)<sup>30</sup> assesses the impact of AD on caregivers of affected children, aged 8 years or younger. The PIQoL-AD adopts a dichotomous response system, which is less sensitive to subtle changes in HR-QoL and includes only items that consider the negative aspects of psychological well-being.

The DFI<sup>31</sup> tool is the tool most widely reported in studies, having been used in over 750 clinical trials, although often at longer intervals despite being

**Table 1** Study-specific information relevant to included assessment tools

References of included publications (first author, year, reference)	Country of origin	Disease of affected patients	Name of measurement instrument	Sample size (n)	Study setting
Eghlileb <i>et al</i> (2009) <sup>26</sup>	UK	Psoriasis	Psoriasis Family Index (PFI-15)	Interviews (unknown)	Monocentric Outpatient clinic
Mrowietz <i>et al</i> (2017) <sup>27</sup>	Germany	Psoriasis	Family Pso	Interviews (14) Piloting (96) Validation (96)	Monocentric Outpatient clinic
Kondo-Endo <i>et al</i> (2009) <sup>28</sup>	Japan	Atopic dermatitis	QoL in Primary Caregivers of children with Atopic Dermatitis	Interviews (unknown) Pilot (33) Validation (400)	Monocentric Outpatient clinic
Chamlin <i>et al</i> (2005) <sup>29</sup>	USA	Atopic dermatitis	Childhood Atopic Dermatitis Impact Scale	Interviews (unknown) Piloting (20) Validation (300)	Two dermatology paediatric practices (San Francisco and Chicago)
McKenna <i>et al</i> (2005) <sup>30</sup>	UK, Netherlands, Italy, Spain, USA, Switzerland, Germany, France (simultaneous development)	Atopic dermatitis	Parent's Index QoL – Atopic Dermatitis	Interviews (65) Piloting (140 total) Validation (ranged between countries 45–328)	Monocentric Outpatient clinic
Lawson <i>et al</i> (1998) <sup>31</sup>	UK	Dermatitis	Dermatitis Family Impact	Interviews (29) and focus groups (10) Piloting (14) Validation (56)	Monocentric Outpatient clinic
References of included publications (first author, year, reference)	Country of origin	Disease of affected patients	Name of measurement instrument	Sample size (n)	Study setting
Ersser <i>et al</i> (2015) <sup>32</sup>	UK	Eczema	Parental Self-Efficacy with Eczema Care Index	Literature review-generation items Piloting and validation (242)	Monocentric Outpatient clinic
Minaya <i>et al</i> (2012) <sup>33</sup>	France	Skin cancer	CareGiver Oncology Quality of Life	Interviews (77) Piloting (837) Validation (unknown)	Monocentric Outpatient clinic
Dufresne <i>et al</i> (2015) <sup>34</sup>	France	Epidermolysis bullosa	Epidermolysis Bullosa – Burden of Disease	Complaints (23) informed item generation Piloting (Lionbridge institution) Validation (55)	Monocentric Outpatient clinic
Dufresne <i>et al</i> (2013) <sup>35</sup>	France	Ichthyosis	Family Burden Ichthyosis	Interviews (94) Piloting (42) Validation (30)	Monocentric Outpatient clinic
Basra <i>et al</i> (2008) <sup>36</sup>	UK	All – general dermatology instrument	Family Dermatology Life Quality Index	Interviews (50) Piloting (20) Validation (14)	Monocentric Outpatient clinic

QoL, quality of life.

validated for use with a 1-week recall period. As most of DFI studies are in secondary care hospitals, there exists the possibility of maximising the chances of the DFI scores showing significant improvements following

an intervention.<sup>31</sup> Dodington's review<sup>37</sup> found that internal consistency and test-retest reliability was adequately demonstrated but highlighted that psychometric measures were less well established due to a lack

**Table 2** Questionnaire-specific information relevant to included assessment tools

Name of measurement instrument	Outcome domains measured	Number of items and subscales	Recall period	Scoring system	Respondent feedback	Admin mode (time in minutes)
Psoriasis Family Index (PFI-15) <sup>26</sup>	Social life, leisure activities, sporting activities, people's reactions, worry about future, housework, relationships treatment duration, clothing shopping and sleep	15 items	Now	4-point scale (0–3)	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Self-administered (2)
Family Pso <sup>27</sup>	Emotional domain – emotional impact. Social domain – impact on daily activities and work/school and treatment. Leisure domain – influence on leisure/ personal relationships	15 items	1 month	5-point Likert format (0–4) and 'Does not apply'	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Self-administered (3)
QoL in Primary Caregivers of children with Atopic Dermatitis <sup>28</sup>	Achievement (3) Worry (6) Family cooperation (3) Exhaustion (8)	19 items	Past week	5-point scale (none to extremely)	Brief in length. Moderate to administer, score and interpret. Conflicting evidence of alternative forms.	Self-report (unknown)
Childhood Atopic Dermatitis Impact Scale <sup>29</sup>	Impact on family (three domains) Sleep and emotions Family and social function	45 items	1 month	5-point scale (never to all the time)	Long in length and problems of acceptability. Moderate to administer, score and interpret. Absent evidence of alternative forms.	Self-administered (6)
Parent's Index QoL – Atopic Dermatitis <sup>30</sup>	One domain – needs that can be influenced by a child with a diagnosis of AD.	28 items	Not reported	5-point scale (never to all the time)	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Self-administered (3)
Dermatitis Family Impact <sup>31</sup>	Personal relationships and helping with treatment, Food and feeding, sleep, housework shopping, financial, leisure tiredness and emotional distress	10 items	1 week	4-point scale (not at all, a little, a lot, very much)	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Self-administered (unknown)
Parental Self-Efficacy with Eczema Care Index <sup>32</sup>	Managing medications Managing eczema and symptoms Communication with healthcare teams Managing personal challenges	29 items four subscales	1 week preintervention and 4 weeks postintervention	11-point Likert Scale	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Clinician administered (3)
CareGiver Oncology Quality of Life questionnaire <sup>33</sup>	Psychological well-being, burden, relationship with healthcare, administration and finances, coping, physical well-being, self-esteem, leisure time, social support and private life	29 items	1 week	5-point Likert scale (never/not at all, rarely/a little, sometimes/somewhat, often/a lot, always/very much)	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Self-administered (3)
Epidermolysis Bullosa – Burden of Disease <sup>34</sup>	Economic and social impact (5) Family life (7) Disease and treatment (5) Child's life (3)	20 items	Not stated	7-point scale (always, very often, often, sometimes, rarely, never and not applicable)	Moderate to administer, score and interpret. Absent evidence of alternative forms. Long in length and problems of acceptability.	Self-administered (unknown)
Family Burden Ichthyosis <sup>35</sup>	Work and psychological impact, daily life, pain, familial and personal relationships	25 items	Not stated	4-point scale (definitely yes, maybe, definitely not and I don't know)	Long in length and problems of acceptability. Moderate to administer, score and interpret.	Self-administered (3)
Family Dermatology Life Quality Index <sup>36</sup>	Housework and expenditure Emotional and physical well-being Impact on study/job, social life burden of care, leisure activities	10 items	1 month	4-point scale (not at all/ not applicable, a little, quite a lot and very much)	Brief in length. Simple to administer, score and interpret. Weak evidence of alternative forms.	Self-administered (3)

QoL, quality of care.

**Table 3** Adequacy of the measurement properties relevant to included assessment tools with excellent and good methodological quality

Name of measurement instrument	Transferability	Reliability	Validity	Structure	Interpretability
Psoriasis Family Index (PFI-15) <sup>26</sup>	Sometimes translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70	Conceptual – well balanced domains. Construct >75% results in accordance with hypothesis. Convergent – no information	IRT. Weak sensitivity to detect changes. Strong item bias.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: not reported.
Family Pso <sup>27</sup>	Never translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC not reported or correlation coefficient <0.70.	Conceptual – more focused on objective/subjective domains. Construct – no information. Convergent <0.70.	Factor analysis. Weak sensitivity to detect changes. Weak item bias.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: not reported
QoL in Primary Caregivers of children with Atopic Dermatitis <sup>28</sup>	Never translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: more focused on objective/subjective domains. Construct <75% results in accordance with hypothesis. Convergent <0.70.	Satisfactory response to change in disease severity. Satisfactory test–retest reliability.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: not reported.
Childhood Atopic Dermatitis Impact Scale <sup>29</sup>	Sometimes translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: well balanced domains. Construct >75% results in accordance with hypothesis. Convergent <0.70.	IRT. Strong sensitivity to detect changes. Weak item bias.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: not reported.
Parent's Index QoL - Atopic Dermatitis <sup>30</sup>	Always translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: more focused on objective/subjective domains. Construct >75% results in accordance with hypothesis. Convergent <0.70.	IRT. Strong sensitivity to detect changes item bias. Strong item bias.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: known in heterogeneous sample.
Dermatitis Family Impact <sup>31</sup>	Always translated using guidelines. Sometimes analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: well balanced. Construct <75% results in accordance with hypothesis. Convergent >0.70.	No factor analysis or IRT. Strong sensitivity to detect changes. Weak item bias.	Norms: General nor dermatology patients. Categorisation: used distribution-based techniques. MCID: not reported.
Parental Self-Efficacy with Eczema Care Index <sup>32</sup>	Always translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: well balanced. Construct <75% results in accordance with hypothesis. Convergent >0.70.	Factor analysis. Satisfactory response to change in disease severity. Weak item bias.	Norms: general nor dermatology patients Categorisation: not reported MCID: not reported.
CareGiver Oncology Quality of Life Questionnaire <sup>33</sup>	Sometimes translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC <0.70.	Conceptual: more focused on objective/subjective domains. Construct <75% results in accordance with hypothesis. Convergent <0.70.	Factor analysis. Low/moderate sensitivity to changes. Weak item bias.	Norms: general nor dermatology patients. Categorisation: used distribution- based techniques. MCID: not reported.
Epidermolysis Bullosa – Burden of Disease <sup>34</sup>	Sometimes translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: well balanced. Construct <75% results in accordance with hypothesis. Convergent <0.70.	Factor analysis. Weak sensitivity to detect changes. Weak item bias.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: not reported.
Family Burden Ichthyosis <sup>35</sup>	Sometimes translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC not reported or correlation coefficient <0.70.	Conceptual: well balanced Construct <75% results in accordance with hypothesis. Convergent <0.70.	No factor analysis or IRT. Weak sensitivity to detect changes. Weak item bias.	Norms: general nor dermatology patients. Categorisation: not reported. MCID: not reported.
Family Dermatology Life Quality Index <sup>36</sup>	Always translated using guidelines. Never analysed in a cultural equivalence study.	IC: 0.95>Cronbach's $\alpha$ >0.70. Retest reliability: k or ICC >0.70.	Conceptual: well balanced domains Construct >75% results in accordance with hypothesis. Convergent <0.70.	Factor analysis. Strong sensitivity to detect changes. Weak item bias.	Norms: general nor dermatology patients. Categorisation: not reported MCID: not reported.

IRT, item response theory; IC, internal consistency; ICC, intraclass correlation coefficient; MCID, minimal clinically important difference.

of vigour in both the creation and validation processes. No valid score-banding descriptors of DFI score meanings are included, and no information to establish the

MCID of DFI score is available.<sup>31</sup> No studies demonstrated dimensionality, factor structure or differential item functioning.

**Table 4** Evaluation of disease-specific and dermatology-specific tools (risk of bias assessment criteria outlined in online supplemental file 4)

Criteria	PFI-15 <sup>26</sup>	Family Pso <sup>27</sup>	QPCAD <sup>28</sup>	CADIS <sup>29</sup>	PiQoL-AD <sup>30</sup>	DFI <sup>31</sup>	PASECI <sup>32</sup>	CarGOQoL <sup>33</sup>	EB-BoD <sup>34</sup>	FBI <sup>35</sup>	FDLQI <sup>36</sup>
<b>Validity</b>											
Conceptual	A	B	B	A	B	A	A	B	A	A	A
Construct	A	C	B	A	A	B	B	B	B	B	A
Convergent	B	B	B	B	B	A	A	B	B	B	B
<b>Interpretability</b>											
Norms	C	C	C	C	C	C	C	C	C	C	C
Categorisation	C	C	C	C	C	B	C	B	C	C	C
MCID	C	C	C	C	A	C	C	C	C	C	C
<b>Reliability</b>											
Internal consistency	A	A	B	A	A	A	A	A	A	A	A
Retest reliability	A	C	A	A	A	A	A	C	A	A	C A <sup>1</sup>
<b>Structure</b>	A	B	B	A	A	C	B	C	B	C	C B
<b>Responsiveness</b>	C	C	B	A	A	A	B	C	C	C	A A
<b>Item bias</b>	A	C	C	C	A	C	C	C	C	C	C C
<b>Cultural issues</b>											
Translations	B	C	C	B	A	A	A	B	B	B	B A
Cultural equivalence	C	C	C	C	C	B	C	C	C	C	C C
<b>Respondent burden</b>	A	A	A	B	A	A	B	B	B	B	B A
<b>Administrative burden</b>	A	A	B	B	A	A	B	B	B	B	B A
<b>Alternative forms</b>	C	C	B	C	C	C	C	C	C	C	C C

Objective and subjective domains are described by Muldoon *et al* (1998).<sup>1</sup>

CADIS, Childhood Atopic Dermatitis Impact Scale; CarGOQoL, The CareGiver Oncology Quality of Life; DFI, Dermatitis Family Index; EB-BoD, Epidermolysis Bullosa Burden of Disease; Family Pso, Family Psoriasis; FBI, Family Burden Ichthyosis; FDLQI, Family Dermatology Life Quality Index; MCID, minimal clinically important difference; PASECI, Parental Self-Efficacy with Eczema Care Index; PFI-15, Psoriasis Family Index; PiQoL-AD, Parents' Index of Quality of Life in Atopic Dermatitis; QoL, quality of life; QPCAD, QoL in Primary Caregivers of Children with Atopic Dermatitis.



The final tool included in this review was the PASECI.<sup>32</sup> It is a generalised self-efficacy scale focusing on the management of four subscales: medication, symptoms, personal challenges and communication with health-care teams. It has a two-factor structure that considers the performance of routine management tasks and the management of child symptoms and behaviour. There was reliance on self-reported data, potentially affecting the fidelity of the results. More research is needed on banding and categorisation.

Validation of the CarGOQoL<sup>33</sup> was carried out using dermatology experts other than caregivers. Several non-optimal indicators of validity are indicated in table 4.

The EB-BoD<sup>34</sup> tool needed to remove non-discriminatory items, such as frustration and guilt, from the original FBI<sup>38</sup> during its creation. It requires further validation in larger EB patient and/or caregiver groups before being revalidated for use in other languages and cultures.

The FBI<sup>35</sup> is the only validated disease-specific questionnaire that measures the concept of burden for ichthyosis caregivers. The monocentric study used parents and their affected children in the creation of verbatim using an unnamed French social assessment, which could not be accessed for this review. Selection bias was a possibility as 40% of participants cared for those affected by severe forms of ichthyosis (severity score 50 or greater). Limitations include that validation of the FBI was carried out using parents of children affected with only the severest forms of ichthyosis. Although itch is one of the significant challenges named by parents of children affected with ichthyosis (third most significant impact during the validation of the DFI),<sup>31</sup> it does not feature as an item. Similarly, no items relate to pain in the finalised FBI.<sup>35</sup> Verification of its psychometric properties, preferably in a multicentre study, is required. Caregiver feedback included that the finalised generation items were negatively phrased. The original French questionnaire has been linguistically and culturally adopted in Italy.<sup>38</sup>

### Dermatology-specific needs assessment tools

The FDLQI<sup>36</sup> is the most used dermatology-specific Health-Related Quality of Life (HR-QoL). The psychosocial impact loaded six items (emotional impact, physical well-being, impact on relationships, leisure, social life and people's reactions) and the physical impact loaded four items (burden, effect on job/study, household expenditure and housework). Fifty semistructured interviews took place that informed the items generated for testing during piloting. The feedback (n=59 items) from these interviews has been termed 'the greater concept'. Piloting of the 19 items occurred with 20 parents or partners of those originally interviewed, potentially introducing bias. Limitations include that the life course of skin disease is not reflected in the FDLQI and that it depends on recall accuracy. Definitions, such as MID, and the meaning of FDLQI scores are missing and future research is required to show the unidimensionality of the tool. The FDLQI

was not tested for responsiveness for clinical change in a hospital or intervention context. Several items cannot discriminate between inflammatory and uninflammatory groups.

One common theme that emerged was the variation in methodological rigour used in measuring informal dermatological caregiver needs. Using the risk of bias assessment, each of the reviewed tools indicated an incomplete psychometric overview meaning that the generalisability and interpretation of results remain limited. Each reviewed tool (11 of 11; 100%) evaluated four or more psychometric properties. They do not comply with the OMERACT filter criteria and consequently are unable to be included in the development of a future Core Outcome Set (COS).<sup>39</sup>

In terms of structure, five tools reported the use of factor analysis.<sup>27 32-34 36</sup> Three tools reported the use of the more recently developed item response theory (IRT) to determine psychometric properties.<sup>26 29 30</sup> Other tools neither reported factor analysis or IRT.<sup>28 31 35</sup> Apart from two tools reporting strong item bias,<sup>26 30</sup> the other nine tools<sup>27-29 31-36</sup> reported weak item bias. One tool<sup>31</sup> reported the use of distribution-based categorisation techniques, but the other 10 tools did not report on categorisation. MCID was not reported for any tool other than one.<sup>30</sup>

In terms of reliability, all tools reported a high internal consistency (IC >0.95). Two tools did not report their retest reliability.<sup>27 35</sup> One reported a weak retest reliability<sup>33</sup> (ICC <0.70), while the other eight tools reported a good retest reliability<sup>26 28-32 34 36</sup> (ICC >0.70). In terms of conceptual validity, four tools have less well-balanced domains.<sup>28-30 33</sup> The other seven tools include well balanced domains.<sup>26 27 31 32 34-36</sup> No information is given regarding the construct validity for one tool.<sup>27</sup> Five tools demonstrate that <75% of results are in accordance with their hypothesis<sup>31-35</sup> and five tools demonstrate that >75% of results are in accordance with their hypothesis.<sup>26 28-30 35</sup> The majority of tools demonstrate poor convergent validity apart from two<sup>31 32</sup> (>0.70). The PFI-15 provides no information on convergent validity.<sup>36</sup> The other eight tools in this review show a convergent validity value of <0.70.<sup>27-30 33-36</sup>

### DISCUSSION

This is the first systematic review to address gaps in the existing evidence base around the identification of appropriate psychosocial needs assessment for caregivers of paediatric patients with dermatological conditions. This topic represents an emerging area for which there is a lack of up-to-date good quality synthesised evidence. With increasing numbers of paediatric patients of chronic skin disease being cared for by informal caregivers, often with limited medical training, key international multidisciplinary stakeholders (including clinicians, dermatological caregivers and policymakers) emphasised an urgent need to improve clinician awareness of existing needs assessment tools, to help them make informed evidence-based



decisions relating to assessment. The need to promote caregiver health outcomes within day-to-day clinical practice has become even more significant during COVID-19, a period of enhanced social isolation and increased caregiver hypervigilance and burnout.

This review identified 11 psychosocial needs assessment tools validated for use among caregivers of paediatric patients with dermatological conditions. A narrative approach was used to arrange the reviewed tools into two groups: dermatology-specific and disease-specific tools. To ease identification of risk of bias, study variability and measurement properties between and within the included tools, results were additionally tabulated using the predefined subheadings on the data extraction forms.

Although skin disease may be characterised at times by unpredictable episodes in symptom severity,<sup>33 34 36</sup> that requires similar systems of monitoring and integrated biopsychosocial support as other chronic conditions,<sup>5 40</sup> our review highlights the lack of literature pertaining to the use of these assessment tools in healthcare settings. This review suggests that the mismatch between the recognised impact of caregiving for skin disease and the failure of practitioners to effectively engage with its management may be attributed to the biomedical model of assessment reflected in existing tools.

In contrast to the tools reviewed,<sup>26–36</sup> which used measures of other constructs as a proxy for caregivers' need, it appears vital to directly assess informal dermatological caregivers' needs (at problem area and support level) and plan for how that knowledge will be used to help support these needs.<sup>41–43</sup> Similarly, future assessments should use the scope of the International Classification of Functioning, Disability, and Health<sup>44</sup> to inform their caregiver framework in terms of contextual factors and in terms of functioning and disability. Despite the recognised difficulty of assessing chronic pathologies by clinical or QoL aspects alone,<sup>45 46</sup> most tools identified in this review were generic QoL tools. The European Academy of Dermatology and Venereology Quality of Life Task Force,<sup>47</sup> Cochrane Skin Centre of Evidence Based Dermatology<sup>48</sup> and the Harmonising Outcome Measures for Eczema initiative<sup>39</sup> reinforce that generic QoL assessments do not encompass the many factors that contribute to the psychosocial burden of skin disease<sup>49</sup> and are not as sensitive, responsive or relevant to individual patients or their caregivers.<sup>50</sup>

We considered appropriate measurement tools to be theoretically driven, rigorously conceptualised with input from caregivers at each stage, consider disease life course, tested for validity and reliability and intended to assess caregiver needs in relevant settings.<sup>39 41 47 48</sup> Conceptual and theoretical work on dermatological caregivers' needs could have been relatively lacking because of the varying degree by which the tools were informed by caregiver experience, with minimal description of the questionnaire development process, absence of or exclusionary key definitions such as family, caregiver and domain and participants were not asked to clarify their relationship

to the patient attending the outpatient clinics. Some of the tools only included items for the negative aspect of psychological well-being.<sup>31 35 36</sup>

Healthcare teams require access to validated assessment tools that consider all dimensions along the care continuum and that do not use measures of other constructs as a proxy for caregivers' needs<sup>51</sup> to provide culturally sensitive care. An international multicentric approach could best address variables including culture, demographics and disease severity. Although none of the reviewed assessment tools allow for the assessment of disease variables, including disease severity, we recommend that future needs assessment tools include disease parameters when designing their assessment framework. Dufresne<sup>35</sup> found that increased disease severity led to increased caregiver burden, suggesting that tools that assess factors relevant to clinical severity of disease could better inform the types of supports needed long term.

Future assessment should be practical and feasible for daily use within busy clinics. A self-reporting psychosocial needs assessment e-tool, developed to identify caregiver needs (at both problem and support level), could best serve to address non-clinical barriers to assessment, including lack of time, support staff and easy tools, to reduce the reported high rates of non-use of validated tools within daily practice.<sup>52</sup> Research reinforces improved care recipient and caregiver outcomes<sup>41–44</sup> when caregivers are facilitated to regularly self-report perceived needs enabling clinicians to identify and/or triage unmet psychosocial care needs.

### Strengths and limitations

Strengths include a published protocol, a multidisciplinary expert group and health science librarian involved in the design of the review, a comprehensive literature search, information provision on study, questionnaire, measurement properties and risk of bias. This review also provides key recommendations for future research. Although time was needed to ensure that members were involved as equal partners in debates and decisions around key issues, benefits of PPI included having experts with lived experience who creatively contributed towards the methodology. Limitations included studies published in the English language between 2000 and 2021.

To enhance the chances of developing a truer set of outcome domains for improved COS uptake, future assessments should adopt a more thorough typology to assess the degree to which deficits in caregivers' needs are present and to develop transparent conceptual frameworks that include key definitions and that are built on a hybrid model using good quality caregiver frameworks alongside qualitative feedback from large and culturally diverse international cohorts of caregivers.<sup>53</sup> With increased emphasis on e-healthcare, it seems both desirable and practical to conceptualise an accessible and solution-based model of future e-assessment that can address recognised healthcare challenges, including limited clinic time, poor caregiver identification and healthcare communication,<sup>53–58</sup> allowing for timely identification and/or triage of unmet psychosocial needs by practitioners

while strengthening a caregiver's sense of autonomy, coping ability and resilience.<sup>59 60</sup> To inform the development of solution-focused assessment e-tools, it is important that research is also conducted into which supports are rated as most important by informal dermatological caregivers.

## CONCLUSION

Although no gold standard tool exists for measuring the psychosocial needs of dermatological caregivers, this comprehensive review improves clinician awareness and knowledge of eleven validated psychosocial needs assessment tools for caregivers of paediatric patients with dermatological conditions. It is hoped that this review will inform the development of solution-based models of outcome assessment for improved dermatology care coordination. As dermatological caregiving research moves forward with significant public and private investment, rigorous measurement of caregivers' needs is essential for the development of social services, public policies and improved COS uptake. These findings have implications for clinical practice, service development and future research and reinforce that attitude towards caregivers is pivotal in developing assessment for the purpose of accessing supports and services.

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### Supplementary file 1: Search Strategy development process

One known relevant systematic review (Sampogna *et al* 2017) was used as a starting point to identify records within databases. A draft search strategy was developed by using candidate search terms that were identified in the titles, abstracts and subject indexing of that systematic review.

**Table 1: Preliminary keywords/search terms identified:**

<p>Psychosocial or psycho-social or psychodermat* or social or cognit* or emotion* or well-being or psychological* or adjust* disorder or depress* or anxiety or anxious or coping or stress or mental health or guilt or embarrassment</p> <p>disease specific or dermatolog* specific or disease burden or burden of disease or scale or needs assessment or psychosocial assessment or index or tool or interview or quality of life or validat* or QoL or measure or impact or screen* or wellbeing or well being or questionnaire or health related quality of life or health profile or inventory or intervention or evaluation or schedule or survey or audit or neuropsychological assessment or activities of daily living or dermatolog* specific health instrument or psychosocial impact or psycho social impact</p> <p>Caregiver* or family or 'family caregiver' or 'family care giver*' or parent or homecare* or home care* or adult or adults* or grownup* or grown up or families or relative or relation* or mother* or father* or family nurs* or primary care provider* or informal caregiver* or carer* or 'greater patient concept' or homecare</p> <p>Child or children or infant* or toddler* or baby or babies or youngster* or young pers* or preschool* or teenage* or adolescen* or prematur* or pediatri*</p> <p>Skin* or skin condition* or skin disorder* or scaliness or keratos* or cornificat* or rare skin dermatology* or chronic disease or chronic condition or long-term condition or chronic illness or incurable or disability or life limiting or long term care or life threatening or palliative or assistive technology or continu* of care or chronic car* or Ichthyos* or continuing car* or impact of chronic skin disease</p> <p>Skindex or measuring the family impact of dermatological conditions or the family impact of skin diseases</p>
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Additional search terms were then identified from the results of that strategy, from the reference list of the systematic review, from systematic searching of each relevant electronic database for relevant “MeSH” terms (included in each search strategy below) and from checking using the PubMed PubReMiner word frequency analysis tool. This strategy was tailored to the specifications of each of the databases searched and developed in collaboration with a subject-specific librarian (J.A.) and expert group. We did not include a specific definition of psychosocial because, given a lack of consensus in the literature on the

use of this term, we wanted to include a diverse range of tools (cognitive, social and emotional) to answer the research question.

Pre-planned keyword searches were limited to titles and abstracts, with MeSH terms being exploded, where available. Each of the keywords above were individually mapped to appropriate subject headings (MeSH) in each database, where available, to ensure a broad and thorough search. Each concept was taken individually and OR MeSH with the keyword(s). This process was repeated with all five concepts and were AND together at the end. The Cochrane RCT filter (reported in the Cochrane Handbook v5.2) was used in the development of the MEDLINE strategy. Independent peer review, by both first and second author, involved proofreading the overall structure, spelling and syntax. The search strategy was validated in MEDLINE when it successfully identified the one known systematic review and three of five further studies (Finlay, 1997; Ashcroft *et al* 1998; De Korte *et al* 2002; Bennett *et al* 2003; Haywood *et al* 2005; Nemeth, 2006) identified as part of the strategy development process.

As per eligibility criteria, the original search strategy was limited to English language studies and from studies published between 01 January 2000 to 01 April 2020. We searched in MEDLINE, PsycINFO and EMBASE using the OVID interface. CINAHL EBSCO (Cumulative Index to Nursing and Allied Health Literature) was additionally searched.

Updated searches were conducted on the 5<sup>th</sup> October 2021 for 01 April 2020 to 5<sup>th</sup> October 2021 (using original search strategies). The PRISMA flow diagram accounts for this updated search and has been included with this submission (Figure 1).

## Supplementary file 2: Database search strategies

### Search Strategy for Embase

1. (Psychosocial or psycho-social or psychodermat\* or social or cognit\* or emotion\* or well-being or psycholog\* or adjust\* disorder or depress\* or anxiety or anxious or coping or stress or mental health or guilt or embarrassment).m\_titl.
2. mental disease/
3. behavior/ or cognitive therapy/ or behavior disorder/
4. social participation/ or social support/ or social alienation/ or "social determinants of health"/ or social support assessment/ or social isolation/ or social psychiatry/ or social aspect/ or social network/ or social psychology/ or social isolation stress test/ or social behavior/ or Social Interaction Anxiety Scale/ or social norm/ or social life/ or social interaction/ or Social Support Index/ or social stigma/ or "social aspects and related phenomena"/ or social phobia/ or social acceptance/
5. cognitive behavioral stress management/ or Social Cognitive Theory/ or cognitive therapy/
6. psychosocial care/ or Psychosocial Adjustment to Illness Scale/ or psychosocial disorder/
7. anxiety/ or anxiety assessment/
8. emotion assessment/ or emotion/
9. wellbeing/ or psychological wellbeing assessment/
10. coping behavior/
11. guilt/
12. emotion/
13. depression/ or depression assessment/
14. psychological adjustment/ or adjustment disorder/ or adjustment/ or Psychosocial Adjustment to Illness Scale/
15. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
16. (disease specific or dermatolog\* specific or disease burden or burden of disease or scale or needs assessment or psychosocial assessment or index or tool or interview or quality of life or validat\* or QoL or measure or impact or screen\* or wellbeing or well being or questionnaire or health related quality of life or health profile or assessment\* or inventory or intervention or evaluation or schedule or survey or audit or neuropsychological assessment or activities of daily living or dermatolog\* specific health instrument or psychosocial impact or psycho social impact).m\_titl.
17. disease burden/
18. exp questionnaire/ or exp "quality of life"/
19. clinical assessment tool/
20. psychological interview/ or interview/
21. exp "quality of life"/
22. health impact assessment/
23. exp needs assessment/
24. health survey/ or health care survey/
25. daily life activity/

26. 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27. clinical assessment tool/
28. 26 or 27
29. (Caregiver\* or family or 'family caregiver' or 'family care giver\*' or parent or homecare\* or home care\* or adult or adults\* or grownup\* or grown up or families or relative or relation\* or mother\* or father\* or family nurs\* or primary care provider\* or informal caregiver\* or carer or 'greater patient concept' or homecare).m\_titl
30. caregiver burden/ or exp caregiver/ or caregiver support/ or Caregiver Strain Index/
31. parent/
32. adult/
33. home care/
34. family functioning/ or family coping/ or family life/ or family centered care/ or family stress/ or family health/ or exp family assessment/or exp family/
35. relative/
36. sibling/
37. grandparent/
38. 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
39. (Ichthyos\* or Skin\* or skin condition\* or skin disorder\* or scaliness or keratos\* or cornificat\* or rare skin dermatology\* or chronicdisease or chronic condition or long term condition or chronic illness or incurable or disability or life limiting or long term care or life threatening or palliative or assistive technology or continu\* of care or chronic car\* or continuing car\* or impact of chronic skin dise).m\_titl.
40. "ichthyosis bullosa of Siemens"/ or X linked ichthyosis/ or ichthyosis/ or lamellar ichthyosis/ or ichthyosis vulgaris/
41. exp skin/ or exp skin disease/
42. psychological rating scale/ or Psychosocial Adjustment to Illness Scale/
43. chronic disease/
44. rare disease/
45. diseases/co, dm [Complication, Disease Management]
46. palliative nursing/
47. eczema/
48. "Psoriasis Area and Severity Index"/ or psoriasis vulgaris/ or Psoriasis Severity Index/ or scalp psoriasis/ or exp psoriasis/
49. atopic dermatitis/ or exp dermatitis/
50. 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
51. (Child or children or infant\* or toddler\* or baby or babies or youngster\* or young pers\* or preschool\* or teenage\* or adolescen\* orprematu\*).m\_titl.



52. exp child/
53. infant/
54. preschool child/
55. toddler/
56. adolescent/
57. baby/
58. 51 or 52 or 53 or 54 or 55 or 56 or 57
59. 15 and 28 and 38 and 50 and 58
60. limit 59 to english language
61. limit 60 to yr="2000 -Current"

**Search Strategy for MEDLINE**

1	mental disorders/ or anxiety disorders/ or dissociative disorders/ or mood disorders/ or neurocognitive disorders/ or neurotic disorders/ or personality disorders/ or sexual dysfunctions, psychological/ or sleep wake disorders/ or substance-related disorders/ or "trauma and stressor related disorders"/
2	Psychiatry/nu, is [Nursing, Instrumentation]
3	exp fatigue/ or exp behavioral symptoms/
4	Stress, Psychological/co, di, ge, mo, nu, px [Complications, Diagnosis, Genetics, Mortality, Nursing, Psychology]
5	Depressive Disorder/nu, px [Nursing, Psychology]
6	Anxiety/ or Anxiety, Separation/ or Anxiety Disorders/ or Performance Anxiety/
7	Personal Satisfaction/
8	Social Stigma/ or Social Support/ or Social Behavior/ or Social Isolation/ or "Social Determinants of Health"/ or Social Perception/ or Psychology, Social/ or Social Marginalization/
9	Depression/nu, px [Nursing, Psychology]
10	Anxiety/ or Stress, Psychological/ or Adaptation, Psychological/ or Depression/
11	Stress, Psychological/nu, px [Nursing, Psychology]
12	Guilt/px [Psychology]
13	Embarrassment/ or Emotions/
14	Behavior, Animal/is [Instrumentation]
15	Cognition Disorders/ or Cognition/
16	Social Stigma/ or Social Values/ or Social Participation/ or Social Behavior Disorders/ or Social Support/ or Social Behavior/ or Social Isolation/ or Social Perception/ or Psychology, Social/ or Phobia, Social/ or Social Skills/ or Social Networking/ or Social Marginalization/
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18	limit 17 to abstracts
19	(Psychosocial or psycho-social or psychodermat* or social or cognit* or emotion* or well-being or psychologic* or adjust* disorder or depress* or anxiety or anxious or coping or stress or mental health or guilt or embarrassment).m_titl.
20	limit 19 to abstracts

21	18 or 20
22	(disease specific or dermatolog* specific or disease burden or burden of disease or scale or validat* or needs assessment or psychosocial assessment or index or tool or interview or quality of life or QoL or measure or impact or screen* or wellbeing or well being or questionnaire or health related quality of life or health profile or inventory or intervention or evaluation or schedule or survey or audit or neuropsychological assessment or activities of daily living or dermatolog* specific health instrument or psychosocial impact or psycho social impact).m_titl.
23	limit 22 to abstracts
24	"Quality of Life"/px [Psychology]
25	"Surveys and Questionnaires"/
26	"Health Services Needs and Demand"/ or Needs Assessment/
27	"Outcome Assessment (Health Care)"/ or Personality Assessment/ or Self-Assessment/ or Nursing Assessment/ or "Process Assessment (Health Care)"/ or Symptom Assessment/ or "Outcome and Process Assessment (Health Care)"/
28	"Severity of Illness Index"/
29	"Tool Use Behavior"/
30	"Quality of Life"/px [Psychology]
31	Interview, Psychological/ or Interview/
32	"Activities of Daily Living"/px [Psychology]
33	23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34	limit 33 to abstracts
35	23 or 34
36	(Caregiver* or family or 'family caregiver' or 'family care giver**or parent or homecare* or home care* or adult or adults* or grownup* or grown up or families or relative or relation* or mother* or father* or family nurs* or primary care provider* or informal caregiver* or carer* or 'greater patient concept' or homecare).m_titl.
37	limit 36 to abstracts
38	Caregivers/px [Psychology]
39	Family/ or Family Health/ or Family Nursing/
40	Parents/px [Psychology]
41	Adult/px [Psychology]
42	Humans/px [Psychology]

43	Siblings/px [Psychology]
44	Grandparents/px [Psychology]
45	38 or 39 or 40 or 41 or 42 or 43 or 44
46	limit 45 to abstracts
47	37 or 46
48	(Ichthyos* or Skin* or skin condition* or skin disorder* or scaliness or keratos* or cornificat* or rare skin dermatology* or chronic disease or chronic condition or long term condition or chronic illness or incurable or disability or life limiting or long term care or life threatening or palliative or assistive technology or continu* of care or chronic car* or continuing car* or impact of chronic skin disease).m_titl.
49	limit 48 to abstracts
50	Ichthyosis/ or Ichthyosis Vulgaris/ or Ichthyosis, X-Linked/ or Ichthyosis, Lamellar/ or "Ichthyosis Bullosa of Siemens"/
51	exp Skin/ or exp Skin Diseases/
52	exp Dermatology/
53	Psoriasis/ or Scalp Dermatoses/
54	exp Dermatitis/ or exp Dermatitis, Atopic/
55	Eczema/
56	Chronic Disease/
57	Rare Diseases/
58	Palliative Care/ or Terminal Care/ or Chronic Disease/
59	50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58
60	limit 59 to abstracts
61	49 or 60
62	21 and 35 and 47 and 61
63	limit 62 to (english language and yr="2000 -Current")
64	exp Child/
65	exp Infant/
66	Child, Preschool/ or Infant/
67	Adolescent/ or Young Adult/
68	Infant, Premature, Diseases/ or Infant, Premature/ or Infant, Extremely Premature/ or Premature Birth/

69	64 or 65 or 66 or 67 or 68
70	limit 69 to abstracts
71	(Child or children or infant* or toddler* or baby or babies or youngster* or young pers* or preschool* or teenage* or adolescen* or prematur*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
72	limit 71 to abstracts
73	21 and 35 and 47 and 61 and 72
74	21 and 35 and 47 and 61
75	limit 74 to (english language and yr="2000 -Current")

### Search Strategy for PsychINFO

<input type="checkbox"/>	1	(Psychosocial or psycho-social or psychodermat* or social or cognit* or emotion* or well-being or psychologic* or adjust* disorder or depress* or anxiety or anxious or coping or stress or mental health or guilt or embarrassment).m_titl.
<input type="checkbox"/>	2	limit 1 to abstracts
<input type="checkbox"/>	3	Psychosocial Factors/ or Major Depression/
<input type="checkbox"/>	4	exp Psychosocial Assessment/
<input type="checkbox"/>	5	Mental Health/ or Well Being/ or Life Satisfaction/ or Anxiety/
<input type="checkbox"/>	6	Psychological Stress/ or Stress/ or Chronic Stress/ or Social Stress/
<input type="checkbox"/>	7	Guilt/
<input type="checkbox"/>	8	exp Embarrassment/
<input type="checkbox"/>	9	Social Identity/ or Social Isolation/ or Social Anxiety/ or Social Cognition/
<input type="checkbox"/>	10	3 or 4 or 5 or 6 or 7 or 8 or 9
<input type="checkbox"/>	11	limit 10 to abstracts
<input type="checkbox"/>	12	2 or 11
<input type="checkbox"/>	13	(disease specific or dermatolog* specific or disease burden or burden of disease or scale or needs assessment or psychosocial assessment or index or tool or interview or quality of life or validat* or QoL or measure or impact or screen* or wellbeing or well being or questionnaire or health related quality of life or health profile or inventory or intervention or evaluation or schedule or survey or audit or neuropsychological assessment or activities of daily living or dermatolog* specific health instrument or psychosocial impact or psycho social impact).m_titl.
<input type="checkbox"/>	14	limit 13 to abstracts

<input type="checkbox"/>	15	Test Reliability/ or Test Validity/ or "Quality of Life"/ or Measurement/ or Psychometrics/ or Questionnaires/
<input type="checkbox"/>	16	exp Caregiver Burden/
<input type="checkbox"/>	17	Questionnaires/
<input type="checkbox"/>	18	exp Rating Scales/ or exp Screening Tests/
<input type="checkbox"/>	19	Rating Scales/ or Screening Tests/
<input type="checkbox"/>	20	exp Needs Assessment/
<input type="checkbox"/>	21	measurement/ or needs assessment/ or "quality of life measures"/ or interviews/
<input type="checkbox"/>	22	"Activities of Daily Living"/
<input type="checkbox"/>	23	Surveys/
<input type="checkbox"/>	24	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
<input type="checkbox"/>	25	limit 24 to abstracts
<input type="checkbox"/>	26	14 and 25
<input type="checkbox"/>	27	(Caregiver* or family or 'family caregiver' or 'family care giver'*or parent or homecare* or home care* or adult or adults* or grownup* or grown up or families or relative or relation* or mother* or father* or family nurs* or primary care provider* or informal caregiver* or carer* or 'greater patient concept' or homecare).m_titl.
<input type="checkbox"/>	28	exp Caregivers/
<input type="checkbox"/>	29	Family/ or Extended Family/ or Family Members/
<input type="checkbox"/>	30	Home Care/ or Home Care Personnel/
<input type="checkbox"/>	31	limit 27 to abstracts
<input type="checkbox"/>	32	28 or 29 or 30
<input type="checkbox"/>	33	limit 32 to abstracts
<input type="checkbox"/>	34	31 or 33
<input type="checkbox"/>	35	(Ichthyos* or Skin* or skin condition* or skin disorder* or scaliness or keratos* or cornificat* or rare skin dermatology* or chronic disease or chronic condition or long term condition or chronic illness or incurable or disability or life limiting or long term care or life threatening or palliative or assistive technology or

		continu* of care or chronic car* or continuing car* or impact of chronic skin disease).m_titl.
<input type="checkbox"/>	36	limit 35 to abstracts
<input type="checkbox"/>	37	exp Skin Disorders/
<input type="checkbox"/>	38	Dermatitis/
<input type="checkbox"/>	39	Chronic Illness/ or Genetic Disorders/
<input type="checkbox"/>	40	Long Term Care/
<input type="checkbox"/>	41	Palliative Care/
<input type="checkbox"/>	42	37 or 38 or 39 or 40 or 41
<input type="checkbox"/>	43	36 or 42
<input type="checkbox"/>	44	12 and 26 and 34 and 43
<input type="checkbox"/>	45	limit 44 to (english language and yr="2000 -Current")



**Search Strategy for CINAHL**

#	Query	Limiters/Expanders
S58	S14 AND S33 AND S44 AND S57	Limiters - Published Date: 20000101-2021105; English Language Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S57	S52 OR S53 OR S54 OR S55 OR S56	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S56	(MH "Dermatology")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S55	(MH "Keratosis+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S54	(MH "Skin+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S53	(MH "Ichthyosis+") OR (MH "Ichthyosiform Erythroderma, Congenital+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S52	ichthyos* or skin* or scaliness or keratos* or cornificat* or dermatolog*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S51	S45 OR S46 OR S47 OR S48 OR S49 OR S50	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S50	(MH "Infant, Premature")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S49	(MH "Adolescence+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S48	(MH "Child, Preschool")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S47	(MH "Infant+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S46	(MH "Child+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S45	child* or infant* or toddler* or baby or babies or youngster* or "young pers*" or preschool* or teen* or adolescen* or prematur* or pediatric* or paediatric*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S44	S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S43	(MH "Primary Health Care")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S42	(MH "Family Nursing")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S41	(MH "Fathers+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S40	(MH "Mothers+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S39	(MH "Adult+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S38	(MH "Home Health Care+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S37	(MH "Parents+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S36	(MH "Family+") OR (MH "Extended Family+") OR (MH "Nuclear Family+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S35	(MH "Caregivers")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S34	caregiver* or family or "family caregiver" or "family care giver*" or parent or homecare* or "home care*" or adult or adults* or grownup* or "grown up" or families or relative* or relation* or mother* or father* or "family nurs*" or "primary care provider*" or "informal caregiver*" or carer* or "greater patient concept" or homecare	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S33	S15 OR S32	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S32	S31 N5 S30	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S31	("disease specific" or "dermatolog* specific" or "disease burden" or "burden of disease")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S30	S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S29	(MH "Activities of Daily Living+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S28	(MH "Audit")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S27	(MH "Surveys+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S26	(MH "Evaluation+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S25	(MH "Psychosocial Intervention")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S24	(MH "Inventories")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S23	(MH "Questionnaires+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S22	(MH "Psychological Well-Being")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S21	(MH "Health Screening+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S20	(MH "Interviews+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S19	(MH "Clinical Assessment Tools+") OR (MH "Research Instruments+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S18	(MH "Scales")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S17	(MH "Needs Assessment")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S16	(MH "Quality of Life+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S15	("disease specific" or "dermatolog* specific" or "disease burden" or "burden of disease") N5 (scale or "needs assessment" or "psychosocial assessment" or index or tool or interview or "quality of life" or validat* or QoL or measure or impact or screen* or wellbeing or "well being" or well-being or questionnaire or "health profile" or inventory or intervention or evaluation or schedule or survey or audit or "neuropsychological assessment" or "activit* of daily living" or "health instrument" or "psychosocial impact" or "psycho social impact")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S13	(MH "Embarrassment")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S12	(MH "Guilt+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S11	(MH "Mental Health")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S10	(MH "Coping+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S9	(MH "Anxiety+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S8	(MH "Depression+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S7	(MH "Adjustment Disorders+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S6	(MH "Adjustment Disorders+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S5	(MH "Stress, Psychological+") OR (MH "Diagnosis, Psychosocial+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S4	(MH "Psychological Well-Being")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S3	(MH "Emotions+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S2	(MH "Social Cognition") OR (MH "Cognition+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S1	psychosocial or psycho-social or psychodermat* or social or cognit* or emotion* or well-being or wellbeing or "well being" or psychologic* or "adjust* disorder" or depress* or anxiety or anxious or coping or stress or "mental health" or guilt or embarrassment	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

#### **Search Strategy for Cochrane Central Register of Controlled Trials (CENTRAL)**

'Skin' AND 'caregiver' AND 'skin disease' AND 'dermatological tool' were searched using the advanced search function.

#### **Search Strategy for U Search**

'Caregiver' AND 'dermatology or skin disease' AND 'measurement tool or assessment tool' AND 'children or adolescents or youth or child or teenager' were searched using the advanced search function.

#### **Search Strategy for Web of Science**

Query preview was '[ALL=(dermatology assessment tools)) AND ALL=(caregivers )]



### Supplementary file 3: Number of records identified during supplementary searches

Grey literature, bibliographies, online databases of QoL tools and several trial registers were searched on 01 April 2020 and updated on 05 Oct 2021.

**Table 1: Records identified during original and updated supplementary searches**

Tools included in search	Search category/term	Records (n) identified during original search (01 Jan 2000 to 01 April 2020)	Records (n) identified during updated search (01 April 2020 to 05 Oct 2021)	Number accessed in full text	Relevant (included in review)
Controlled Trials ISRCTN ( <a href="http://www.controlled-trials.com/isrctn/">www.controlled-trials.com/isrctn/</a> )	'Skin and Connective Tissue Diseases'	241	2	3	0
United Kingdom (UK) Clinical Trials Gateway ( <a href="http://www.ukctg.nihr.ac.uk/default.aspx">www.ukctg.nihr.ac.uk/default.aspx</a> )	'Skin and Cosmetic health'	72	2	0	0
United States(US) National Institutes of Health Ongoing Trials Register ( <a href="http://www.clinicaltrials.gov">www.clinicaltrials.gov</a> )	'caregiver' and 'skin diseases'	24	0	1	0 (recruitment stage)
Australian New Zealand Clinical Trials Registry ( <a href="http://www.anzctr.org.au">www.anzctr.org.au</a> )	'caregiver' and 'skin'	25	0	0	0
World Health Organization International Clinical Trials Registry platform ( <a href="http://www.who.int/trialsearch">www.who.int/trialsearch</a> )	'skin' and 'caregiver'	182	1	0	0
EU Clinical Trials Register ( <a href="https://www.clinicaltrialsregister.eu/">https://www.clinicaltrialsregister.eu/</a> )	'skin' and 'caregiver'	30	1	0	0
British Library Electronic Theses Online Service (EThOS) was searched using several combinations of key words	skin, instrument, caregiver, validation, psychosocial	0	2	2	0
OpenGrey database ( <a href="http://www.opengrey.eu/">www.opengrey.eu/</a> ) was searched (up to 22 November 2013)	'Skin Diseases'	89	1	0	0
Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID) (2002)		0	0	0	0
Handsearching of the bibliographies of included and excluded studies		48	3	0	0
<b>Total</b>		<b>711</b>	<b>12</b>	<b>6</b>	<b>0</b>



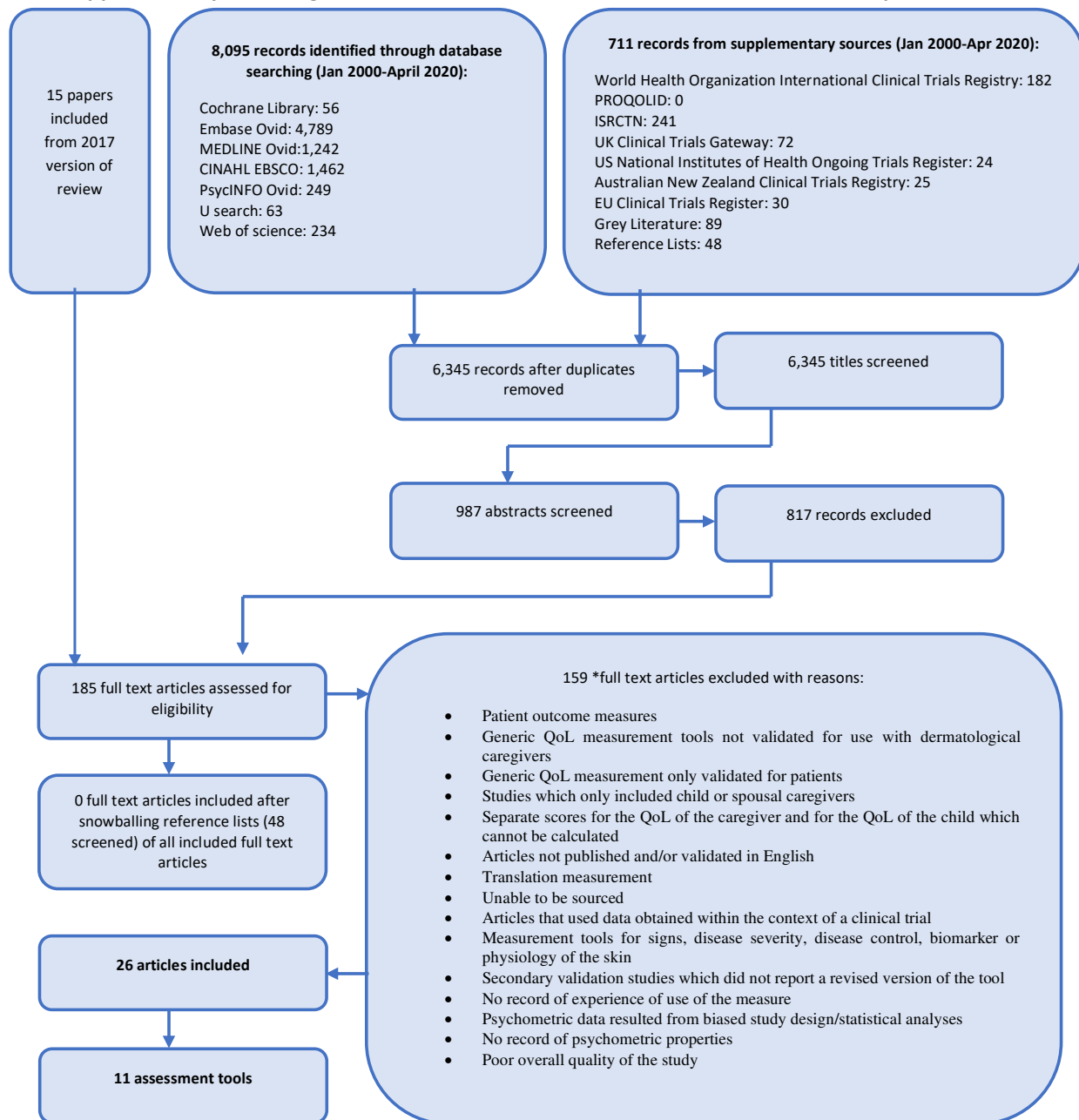
## Supplementary file 4: Methodological domains of the risk of bias criteria

Domains	Definitions	Grades and Criteria		
Validity Conceptual <sup>1</sup> Construct <sup>2</sup> Convergent <sup>3</sup>	Does the tool measure what it is supposed to measure? Are the relevant domains captured? Does tool confirm hypothesized difference (eg diagnosis, clinical disease severity, others) Does the tool relate to other tools measuring the same construct?	A1: well balanced, objective and subjective domains B1: more focused on objective or subjective domains C1: missing important HRQOL domains	A2:>75% of results are in accordance with specific hypotheses B2: <75 of results are in accordance with specific hypotheses C2: no information	A3: correlation> B3: correlation < C3: no information
Interpretability Norms Categorization MCID <sup>4</sup>	Are there standard comparative data from the general population and/or dermatology patients published and/or available? Are there categories of the obtained score available? Has the minimal change that is relevant to patients been reported?	A1: general and dermatology patients B1: general or dermatology patients C1: general nor dermatology patients	A2: using anchor or banding techniques B2: using distribution-based techniques C2: not reported	A3: MCID is known in heterogeneous sample B3: MCID is known in limited sample C3: not reported
Reliability <sup>3,6</sup> Internal consistency Retest-reliability	Does the tool provide a consistent answer? The extents to which items in a (sub) scale are intercorrelated, thus measuring the same construct (Cronbach's x)? Does a repeated administration of the tool within a reasonable period result in a similar outcome?	A1: 0.95>Cronbach's x>0.70 B1: Cronbach's x<0.7 or >0.95 C: Cronbach's x not reported	A2: x or ICC >0.7 B2: x or ICC <0.7 or correlation coefficients >0.7 C2: x or ICC not reported or correlation coefficient <0.7	
Structure	Have the domains and/or summary score of the tool been confirmed?	A: item response theory B: Factor analysis C: no factor analysis or item response theory		
Responsiveness	Is the tool sensitive to detect changes over time or due to therapy using patient centred and/or clinical criteria?	A: strong B: moderate or conflicting evidence C: absent, weak or solely based on statistical evidence		



Domains	Definitions	Grades and Criteria	
Item bias	Do the items of the tool function similar across external factors such as age, gender and diagnosis?	A: strong B: moderate or conflicting evidence C: absent or weak	
Cultural issues Translations Cultural equivalence	Has the tool been translated using guidelines? Has the tool been analysed in a cultural equivalence study?	A1: always B1: sometimes C1: never, not reported	A2: always B2: sometimes C2: never
Respondent burden	Is the length and content acceptable to the patients?	A: brief (<15min) B: long or problems of acceptability C: long and problems of acceptability	
Administrative burden	How easy is the tool to administer, score and interpret?	A: simple B: moderate C: complex	
Alternative forms	Is the tool available and tested for alternate forms of administration such as interviews in person or telephone, self-administration or computer-assisted interviews	A: strong evidence B: moderate or conflicting evidence C: absent or weak evidence	
<p><b>Legend:</b> ICC, intraclass correlation coefficient; <sup>1</sup> Adjusted from Lohr et al (1996); Andresen (2000) and Terwee et al (2007); <sup>2</sup> Objective and subjective domains are described by Muldoon et al (1998); <sup>3</sup> Criteria of construct validity and reliability were based on description by Terwee et al (2007); <sup>4</sup> MCID, minimal clinically important difference (ie the minimal difference, which is measured and is relevant to a patient and is not due to intrinsic variance of the instrument); <sup>5</sup> Refer to Table 2; <sup>6</sup> Reliability is concerned with the temporal stability of instrument scores (test-retest) and internal consistency, which is estimated by Cronbach's <math>\alpha</math>, evaluates the relationship between all items (of a scale) and their ability to measure a single underlying domain. Test-retest reliability assess score consistency over two points in time assuming no change in health status and may provide a more rigorous of reliability due to the different sources of variance. Test-retest reliability should best be expressed in a <math>\kappa</math> coefficient or ICC. Spearman's correlation coefficients are less optimal for retest reliability.</p>			

## Supplementary file 5: Figure 1: PRISMA Flow Chart for initial search (Jan 2000-April 2020)

**Figure 1 Legend:**

PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.; CINAHL, Cumulated Index to Nursing and Allied Health Literature; EBSCO, Elton B. Stephens Company; PsycINFO, Psychological Information Database; U Search, Ulster University Search; PROQOLID, Patient-Reported Outcome and Quality of Life Instruments Database; ISRCTN, International Standard Randomised Controlled Trials Number; UK, United Kingdom; US, United States; EU, European Union; QoL, Quality of Life.

### New studies included from updated search

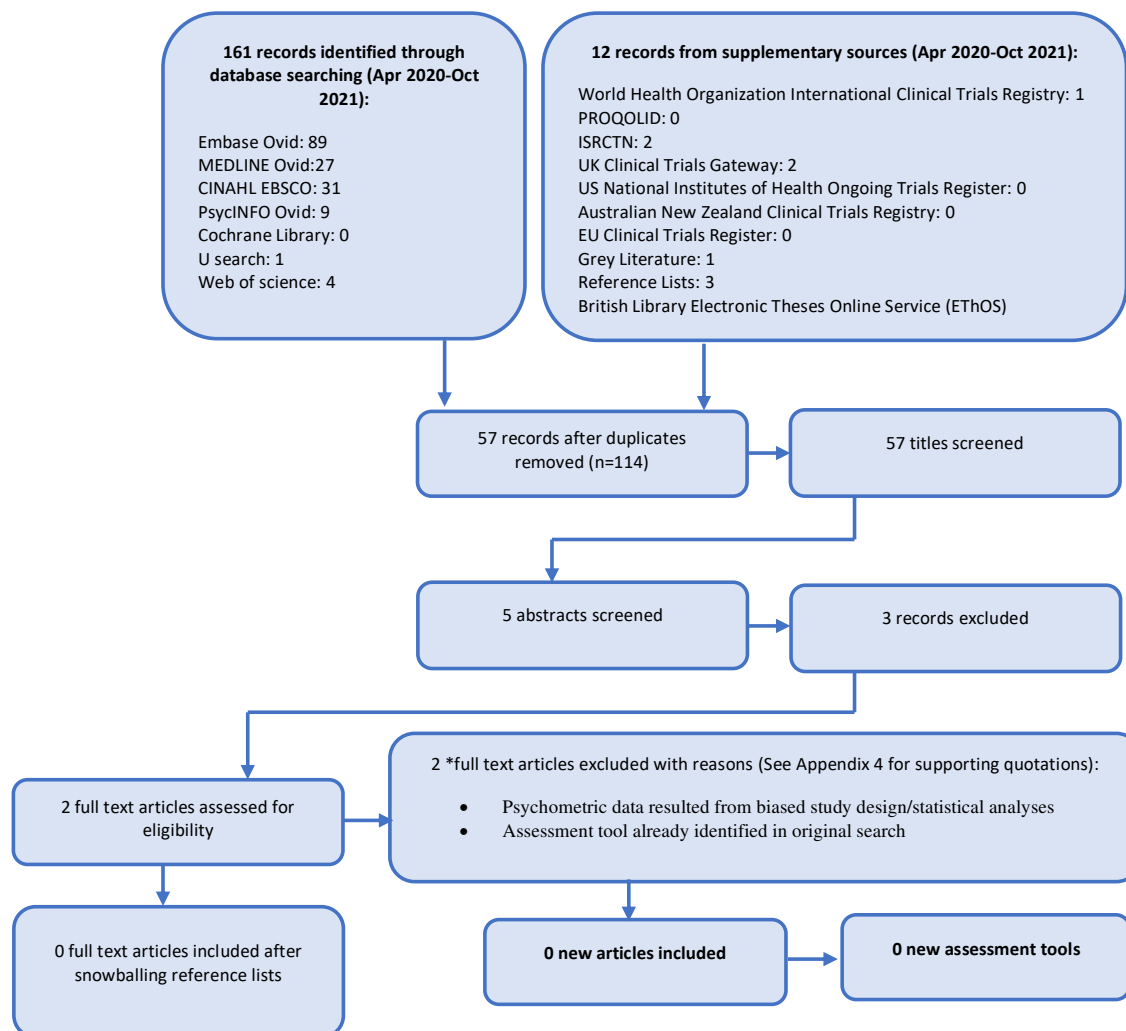
During the updated search, a total of 173 records were identified. 161 records were identified from database searches and an additional 12 records were identified from supplementary searches. In total, 57 records were available after duplicates (n=114) were removed. 57 titles were screened. 5 abstracts were screened and 2 full text record were assessed for eligibility.<sup>1,2</sup>

One record<sup>1</sup> identified no new measurement tool, with the **Family Dermatology Life Quality Index (FDLQI) already included in our initial search**. The second record<sup>2</sup> was excluded for a reason as listed in the exclusion criteria in Figure 1 (psychometric data resulted from biased study design). This exclusion was also justified by quotations from the paper ('Validity was established in a limited range of subjects', 'the parents that responded to the survey were all mothers', 'The present study was a single-institution cross-sectional study in Japan targeting parents of infants and toddlers (first-time patients less than 7 years old)').

In summary, no new studies and no new assessment tools were identified in our updated review. Please see PRISMA flow diagram (fig.2) below.

### References

1. Zychowska M, Reich A, Maj J, Jankowska-Konsur A, Szepietowski J. Impact of Childhood Psoriasis on Caregivers' Quality of Life, Measured with Family Dermatology Life Quality Index. *J Eur Acad Dermatol Venereol* 2020; 100.
2. Sato H, Goto A, Murakami M, Kawabata Y. Development of a Pediatric Dermatology Screening tool based on Two Parent-Reported Skin Symptoms: Comparison of Parental Recognition and Physician Diagnosis of Skin Symptoms of Infants and Toddlers. *J Prim Care Community Health* 2020;11: 1-7.

**Figure 2: PRISMA Flow Diagram for updated search (01 Apr 2020 to 05 Oct 2021)****Figure 2 Legend:**

PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.; CINAHL, Cumulated Index to Nursing and Allied Health Literature; EBSCO, Elton B. Stephens Company; PsycINFO, Psychological Information Database; U Search, Ulster University Search; PROQOLID, Patient-Reported Outcome and Quality of Life Instruments Database; ISRCTN, International Standard Randomised Controlled Trials Number; UK, United Kingdom; US, United States; EU, European Union.