Patient-reported outcome measures for health-related quality of life in patients with psoriasis: a systematic review

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Patient-Reported Outcome Measures for Health-Related Quality of Life in Patients With Psoriasis
A Systematic Review

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IMPORTANCE Multiple patient-reported outcome measures (PROMs) for health-related quality of life (HRQL) exist for patients with psoriasis. Evidence for the content validity and other measurement properties of these PROMs is critical to determine which HRQL PROMs could be recommended for use.

OBJECTIVE To systematically review the validity of HRQL-focused PROMs used in patients with psoriasis.

EVIDENCE REVIEW Using PubMed and Embase, full-text articles published in English or Spanish on development or validation studies for psoriasis-specific, dermatology-specific, or generic HRQL PROMs were included. Development studies included original development studies, even if not studied in psoriasis patients per Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) recommendations. If a study included multiple diagnoses, more than 50% of patients had to have psoriasis or psoriasis-specific subgroup analyses available. Data extraction and analysis followed the COSMIN guidelines. Two independent reviewers extracted and analyzed the data, including PROM characteristics, quality of measurement properties (structural validity, internal consistency, cross-cultural validity, reliability, measurement error, criterion validity, construct validity, and responsiveness), and level of evidence. PROMs were classified into 3 levels of recommendations: (1) PROM recommended for use; (2) PROM requires further validation; and (3) PROM not recommended for use.

FINDINGS Overall, 97 articles were identified for extraction. This included 19 psoriasis-specific, 8 skin-specific, and 6 generic PROMs. According to COSMIN standards, most measures identified received a B recommendation for use, indicating their potential but requiring further validation. Only the Rasch reduced version of the Impact of Psoriasis Questionnaire (IPSO-11 Rasch) received an A recommendation for use given that it had sufficient content validity, structural validity, and internal consistency.

CONCLUSIONS AND RELEVANCE This study identified a significant lack of information concerning the quality of HRQL measures in psoriasis. This gap in knowledge can be attributed to the fact that traditional measures were developed using validation criteria that differ from the current standards in use. Consequently, additional validation studies in accordance with contemporary standards will be useful in aiding researchers and clinicians in determining the most suitable measure for assessing HRQL in patients with psoriasis.

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The International Dermatology Outcome Measures (IDEOM) initiative is developing a Core Outcome Set for use in psoriasis clinical trials and longitudinal observational studies. This process consists of 2 consecutive steps: (1) identifying a core set of domains and (2) selecting the most appropriate instrument to measure these domains.[1] Selecting the right outcomes and valid measures for each domain is of paramount importance in the planning of clinical trials, as it enables direct comparison of interventions.[1] It is also important that the selected outcomes hold significance for key stakeholders, including patients and clinicians.

In 2018, IDEOM published a core domain set for psoriasis clinical trials and is now working on selecting instruments for identified domains. The domains included in the set consist of skin manifestations, psoriasis, and psoriatic arthritis (PsA) symptoms, investigator global, patient global, treatment satisfaction, and health-related quality of life (HRQL).[2]

HRQL is a complex and multidimensional construct that captures individuals' quality of life relative to their health or disease status.[3,4] Wilson and Cleary[5] have developed one of the most frequently used conceptual models of HRQL. This model describes 5 levels of outcomes including biological and physiological factors, symptoms, functioning, general health perceptions, and overall quality of life. In this review, we defined HRQL as symptoms (physical or mental), physical functioning, social functioning (ie, interpersonal interactions/activities), role functioning (ie, academic/work achievement), and overall quality of life.

Psoriasis exerts a significant effect on a patient's HRQL.[6-11] Understanding a patient's current HRQL status is critical to support optimal disease management, informing patient-physician discussions, and delivering high-quality care.[3,8,10-14] Accordingly, multiple treatment guidelines have recommended HRQL measurement during routine psoriasis care.[15-18]

To date, numerous psoriasis-specific, dermatology- or skin-related quality of life (SRQL), and generic patient-reported outcome measures (PROMs) have been used to measure HRQL in patients with psoriasis. However, little is known about which of these measures might be most appropriate to evaluate HRQL among patients with psoriasis. To establish which HRQL PROMs are best validated and guide future validation efforts, we sought to systematically review and assess the measurement properties of HRQL PROMs used in psoriasis in accordance with the Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) guidelines.[19-21]

Key Points

Question What are the measurement properties of existing patient-reported outcome measures that assess health-related quality of life in patients with psoriasis?

Findings In this systematic review, almost all health-related quality of life measures for psoriasis were missing evidence for key measurement properties according to Consensus-Based Standards for the Selection of Health Measurement Instruments Guidelines; this gap in knowledge may arise from the fact that most of these measures, including those used routinely for registration trials, were developed using validation criteria that differ from the current standards in use.

Meaning Further work is needed to demonstrate the validity, reliability, and responsiveness of other health-related quality measures in patients with psoriasis.

Methods

Protocol and Registration

The review protocol was registered on PROSPERO (CRD42017075580). This study did not require ethics approval.

Literature Search

This review followed the COSMIN guideline for conducting systematic reviews of PROMs.[19] PubMed and Embase (OVID) databases were used (eMethods 1 in the Supplement). The overall search strategy aimed to (1) identify all PROMs used for HRQL in psoriasis (stage 1) and (2) identify development and validation studies for these identified PROMs (stage 2).

Study Selection

Abstract screening was conducted in Covidence by 2 independent reviewers. In cases of disagreement, the full-text article was retrieved and screened. Full-text screening and data extraction was performed by 2 independent reviewers (L.M.P.-C., J.S.B., and/or Z.H.H.). In cases of disagreement, the reviewers discussed the case, and if needed, a third reviewer was queried.

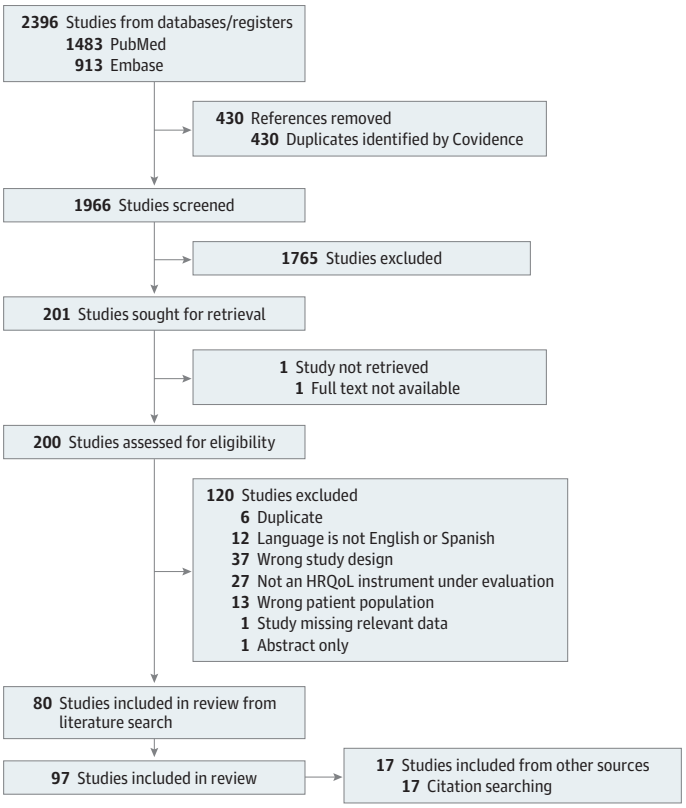
We included any full-text article published in English or Spanish that investigated development or evaluation of measurement properties for a PROM assessing HRQL in patients with psoriasis. In studies investigating multiple dermatologic conditions, psoriasis had to be present in 50% or more of the patients, or subgroup analyses on psoriasis-specific data had to be available. In addition, studies were required to report on a PROM that aimed to measure HRQL. Only multidimensional instruments that assessed 2 or more aspects of HRQL per the Wilson and Cleary model were included. PROMs that measured only 1 aspect of HRQL (eg, only mental health or work productivity) were excluded.

Study population could include children, adolescents, or adults. Development studies could include original development studies, even if not studied in psoriasis patients per COSMIN recommendations.[19-21] Studies that only used the PROM as an outcome measurement or where PROMs were included only to validate a new PROM or other PROMs were excluded. PROMs tested among patients with PsA only were excluded. Psoriasis-specific instruments were defined as those developed for use only among patients with psoriasis and measuring psoriasis-related HRQL status. SRQL instruments were defined as instruments that were developed in patients with dermatologic conditions to measure cutaneous disease-mediated HRQL. General HRQL instruments were considered those that were developed for use in patients with any variety of medical conditions and were not specific to any 1 condition or organ system.

Risk of Bias

The methodological quality of the included studies was evaluated using the COSMIN Risk of Bias checklist.[20,21] Each study could be rated as very good, adequate, doubtful, or inadequate. Disagreements were discussed until consensus was reached. For structural validity and internal consistency, the instruments' measurement model (reflective vs formative) was considered. Reflective scales reflect the latent construct, ie, changes in HRQL caused changes in the

Figure 1. PRISMA Flow Diagram



HRQoL indicates health-related quality of life.

item scores measured. Formative (sometimes called "causal") models measure items that directly cause changes in HRQL.[22] We characterized each instrument's original description as reflective or formative. However, when a description was not available, this determination was made by the authors using guidance such as the thought test.[23] Structural validity and internal consistency were not evaluated for formative instruments.[22-24] If the instrument contained a mix of reflective and formative items and structural validity and internal consistency were reported, the instrument was assumed to be based on a reflective model and such measurement properties were evaluated.[20]

Evaluation of Measurement Properties

We assessed the following properties for each PROM development or validation study: content validity, internal consistency, structural validity, construct validity, cross-cultural validity, reliability, measurement error, and responsiveness.[20] Spanish translation, if required, was performed by 2 coauthors (J.S.B. or L.M.P-C.). PROM versions in specific languages were considered separate PROMs for data extraction and analysis.

The results of each study on a measurement property were extracted and evaluated using the Criteria for Good Measurement Properties. Accordingly, each result was rated as sufficient, insufficient, or indeterminate.[19] Results from individual studies were then qualitatively summarized by measurement property per PROM. The summarized result was also compared against the same criteria and rated as sufficient, insufficient, indeterminate, or inconsistent. For hypothesis-based construct validity testing, the acceptable degree of correlation between PROMs was established a priori (eMethods 2 in the Supplement). Relatedly, hypothesis testing comparisons should be guided by the quality of the comparator. For details on comparator quality assessment and definitions see eMethods 3 in the Supplement.

To assess the comprehensiveness of PROMs, we established a priori a minimum set of domains that should be assessed by a given PROM to receive a positive rating for comprehensiveness. We defined the minimum set of required domains based on the HRQL model proposed by Wilson and Cleary, the most frequently used conceptual model of HRQL.[5] Accordingly, the comprehensiveness of a PROM would be rated positive if it included at least 1 item for the following domains: symptoms, physical functioning, social functioning (ie, interpersonal interactions/activities), role functioning (ie, academic/work achievement), depression or anxiety, and body image.

Grading the Quality of Evidence

The quality of evidence for the summary score of each PROM was rated as high, moderate, low, or very low according to modified GRADE guidelines.[19,20] These ratings are based on 4 factors: risk of bias (ie, quality of the studies), consistency of results from studies, directness (different populations, interventions, or outcomes than those of interest to the review), and precision (width of confidence intervals).

Recommendation For Use of PROMs in Psoriasis

Each PROM was assigned to 1 of the 3 standardized COSMIN recommendations for use categories.[19] Category A: the PROM can be rec-

Table 1. Characteristics of the Psoriasis-Specific Measures

PROM	Construct(s)	Target population	Recall period	(Sub)scale(s) (No. of items)	Response options	Range of scores	Language versions validate in psoriasis
EQ-5D-Pso[47]	Health state	Adults and adolescents with psoriasis	Currently	Skin irritation (1), self-confidence (1) mobility (1), self-care (1), usual activities (1), pain/discomfort (1), and anxiety and/or depression (1)	5-Point adjectival scale	The 7 descriptive states are summarized with a 7-digit number that describes a health state	Hungarian and UK English
I-BOP[66]	Disease burden from psoriasis	Adults with psoriasis vulgaris	Not specified	1 Scale (10)	7-Point adjectival scale	0-70	French and US English
IPBOD[92]	Disease burden from inverse psoriasis	Adults with inverse psoriasis	Not specified	1 Scale (16)	VAS with line marked at never and all the time; does not apply to me given as an option	NA	US English
IPSO-16[86]	Psychosocial effect of psoriasis	Adults with psoriasis	Specified in item: daily, last month	Physical (3), psychological (8), social components (5)	5-Point adjectival scale	0-64	Italian and US English
IPSO-10 CTT[86]	Psychosocial effect of psoriasis	Adults with psoriasis	Specified in item: daily, last month	Mental functioning (3), mental well-being (3), stigmatization (4)	5-Point adjectival scale	0-40	US English
IPSO-11 Rasch[86]	Psychosocial effect of psoriasis	Adults with psoriasis	Specified in item: daily, last month	1 Scale (11)	3-Point adjectival scale	0-22	US English and Italian
NPQ10[45]	HRQL, mostly role functioning (9/10 questions)	Children, adolescents, and adults with nail psoriasis	Not specified	1 Scale (10 items with 1 question regarding psoriasis location)	3-Point adjectival scale	0-20	French
NAPPA[72]	3 Modules: HRQL, needs and treatment benefits, objective nail status	Adults with nail disease and/or psoriatic arthritis	Not specified	HRQL: signs (6), stigma (7), everyday life (7); needs and treatment: unidimensional (24)	5-Point adjectival scale	Each scale 1-5 and overall is the mean	German, English, Danish, Japanese, Italian, and Spanish
PDI[40]	Psoriasis disability	Adults with chronic psoriasis	4 wk	Daily activities (5), work or school (3), if not at work/school (3), personal relationships (2), leisure (4), treatment (1)	4-Point adjectival scale	0-45	UK English, Chinese, Italian, Norwegian, Persian, Serbian, Sinhala, US English, UK English, Italian, and Turkish
PLSI[104]	Psoriasis-related stress	Adults with psoriasis	4 wk	1 Scale (15)	4-Point adjectival scale	0-45	Italian, US English, and UK English
PQLQ[43]	HRQL, role-functioning	Adults with an Islamic background	4 wk	1 Scale (18)	Each item has a yes/no component; if yes then 4-point adjectival scale was completed	0-54	Turkish
P-SIM[44]	Psoriasis signs/symptoms/effect	Adults with psoriasis vulgaris	24 h (Daily diary)	1 Scale (14)	NRS (0-10)	Each scale 0-10	US English
PSOdisk[78]	HRQL, items labeled broadly encompassing role functioning, emotional effect, and symptoms/signs	Patients with psoriasis vulgaris	1 wk	Each question independent (10)	11-Point adjectival scale	No score; area of the polygon is used qualitatively to represent severity	Italian
PSO-LIFE[109]	HRQL, emotional effect, symptoms/signs	Patients with psoriasis	1 wk	1 Scale (20)	5-Point adjectival	20-100 (Transformed to 0-100)	Spanish

(continued)

ommended for use; category B: the PROM has the potential to be recommended for use but requires further validation, and category C: the PROM should not be recommended for use. An A-level recommendation for use is defined as the PROM having evidence for sufficient content validity (any level of evidence quality) and at least low-quality evidence for sufficient internal consistency. A C-level recommendation is defined as the PROM having high-quality evidence demonstrating insufficient measurement criteria, and a B-level recommendation is de-

Table 1. Characteristics of the Psoriasis-Specific Measures (continued)

PROM	Construct(s)	Target population	Recall period	(Sub)scale(s) (No. of items)	Response options	Range of scores	Language versions validate in psoriasis
PSORIQoL[48]	Psoriasis-related needs-based quality of life	Adults with psoriasis	Not reported	1 Scale (25)	True/false	0-25	UK English, US English
PQOL-41[95]	HRQL	Adults with psoriasis	4 wk	Emotional (10), body image and social acceptability (6), overall psychosocial (6), day-to-day activities (11), day-to-day physical effects (8)	NA	NA	US English
PQOL-12[95]	HRQL, emotional effect, signs/symptoms, functioning (1 item)	Adults with psoriasis	4 wk	Quality of life (8), symptoms (4)	0 (Not at all) to 10 (very much)	0-120	US English, Indian
QLICD-PS (V2.0)[46]	HRQL	Adults with psoriasis	Not specified	Physical function (9), mental function (11), social function (8), specific symptoms/treatment adverse effects/psychosocial effect of psoriasis (13)	5-Point adjectival scale	0-100	Chinese
QualiPso[110]	HRQL, assesses role functioning, emotional effect, effect of therapy, disease signs/symptoms	Adults with psoriasis	Not specified	Social life (20), mental health (12), treatment outcome (4), skin symptoms (3)	4-Point adjectival scale	Social life (20-80), mental health (12-48), treatment outcomes (4-16), skin symptoms (3-12)	French

Abbreviations: BOP, individual burden of psoriasis; EQ-5D-Pso, psoriasis-specific EuroQol 5-dimensional questionnaire; I-HRQL, health-related quality of life; IPBOD, inverse psoriasis burden of disease; IPSO-16, impact of psoriasis questionnaire (16 questions); IPSO-10 CTT, impact of psoriasis questionnaire (10 questions, derived using Classic Test Theory); IPSO-11, Rasch impact of psoriasis questionnaire (11 questions, derived using Rasch methods); NPQ10, nail psoriasis quality of life scale; NA, not available; NAPPA, nail assessment in psoriasis and psoriatic arthritis; NRS, Numeric rating scale; PDI, psoriasis disability index; PLSI, psoriasis life stress inventory; PQLQ, psoriasis quality of life questionnaire; P-SIM, psoriasis impact and symptoms measure; PSORIQoL, psoriasis quality of life scale; PQOL, psoriasis quality of life (41 items); PQOL-12, psoriasis quality of life (12 items); PROM, patient-reported outcome; QLICD-PS (V2.0), psoriasis-specific quality of life instruments for chronic diseases version 2; VAS, visual analogue scale.

fined as any PROM not meeting criteria for an A-level or C-level recommendation.

Results

Study Selection

A systematic literature review was performed on March 23, 2023. We identified 2396 abstracts; after removing duplicates, 1966 abstracts remained for screening. After screening, 80 full-text studies were identified and an additional 17 studies were added after searching references (**Figure 1**).[25-121]

Study Characteristics

We identified 19 psoriasis-specific PROMs, 8 SRQL, and 6 generic PROMs that were developed and/or validated in psoriasis (**Table 1**[40,43-48,66,72,78,86,92,95,104,109,110] and **Table 2**[41, 42, 57, 67, 85, 91, 93, 94, 96, 97, 108, 131-133]). All measures were self-reported except for the Psodisk, which is designed to be used during the patient visit together with the clinician. Most measures were developed and scaled using classical test theory (CTT) except the IPSO-11 Rasch and the Skindex-17, which used Rasch methods and Item Response Theory. Most measures were multidomain and used an adjectival scale (Table 1). All PROMs were multi-item instruments.

Among psoriasis-specific PROMs, most measures addressed psoriasis vulgaris, except the IPBOD (inverse psoriasis),[92] the Nail Psoriasis Quality of Life Scale (NPQ10),[45] and the Nail Assessment in Psoriasis and Psoriatic Arthritis Quality of Life (NAPPAQOL)[72] scales (nail psoriasis). All instruments were developed using adult patients with psoriasis except the NPQ10, which included children and adolescents.[45] HRQL was generally represented by emotional effect, role functioning, social functioning, disease signs, and symptoms.

Risk of Bias, Evaluation of Measurement Properties, and Quality of the Evidence

Content validity scores are shown in **Figure 2** and **Figure 3** and eTable 1 in the Supplement. For psoriasis-specific measures, 4 of the PROM development studies were rated as doubtful (PsoLife,[109] PSORIQoL [UK English],[48] PSORIQoL [US English],[49] PQOL12 [US English][95]), and the remaining were rated as inadequate. We identified 3 content validity studies. The content validity study for the EQ-5D-Pso (Hungarian)[27] was of very good quality, whereas the content validity studies for the PDI (Norwegian)[101] and PSORIQOL (US English)[49] were of doubtful quality. Overall content validity (combined evidence from development and content validity study) was sufficient for 4 psoriasis-specific PROMs (IPSO-16 [US English],[98] IPSO 10 CTT [US English],[86] IPSO 11 Rasch [US English],[86] and the PQOL41 [US English][95]), with very low level of evidence.

For SRQL and generic instruments, all PROM development studies were of doubtful or inadequate quality. We identified 4 content

Table 2. Characteristics of the Dermatology Specific and Generic Measures

PROM	Constructs	Target population	Recall period	(Sub)scale(s) (No. of items)	Response options	Range of scores	Language versions validate in psoriasis
Dermatology specific							
DLQI[41]	SRQL	Patients aged ≥16 y with skin disease	7 d	1 Scale (10)	4-Point adjectival scale	0-30	US English, UK English, Brazilian, Chinese, Dutch, Farsi, German, Hungarian, Italian, Norwegian, Serbian, Spanish, Swedish, Ukrainian, Moroccan
DQOLS[42]	SRQL	Adolescents and adults with skin disease	Currently	Psychosocial (17), activities (12), symptoms (12)	5-Point adjectival	0-100	UK English
FLQA-core[108]	SRQL	Adults with skin diseases	1 wk	Physical complaints (7), daily life (3), social life (3), mental health situation (9), treatment of skin disease (3), satisfaction (6)	5-Point adjectival scale	Each scale 1-5	German
ISDL[97]	SRQL	Patients aged ≥16 y with skin disease	Varies by item, most 4 wk	Physical functioning (9), physical symptoms (6), scratch response (6), psychological functioning (16), stressors (16), illness cognition (18), social support (6)	Physical functioning: 4-point adjectival scale; physical symptoms: 10-cm VAS; scratch response 4-point adjectival scale; psychological functioning: 4 and 5-point adjectival scales; stressors: 4-point adjectival scale; illness cognitions: 4-point adjectival scale; social support: 4-point adjectival scale	Not specified	Dutch
Scalpdex[91]	Scalp-disease related HRQL	Adults with scalp dermatoses	1 mo	Symptoms (3), emotions (15), functioning (5)	5-Point adjectival scale	Each domain 0-100	Italian
Skindex-16[67]	SRQL	Adolescents and adults with skin disease	1 mo	Symptoms (5), emotions (6), functioning (5)	7-Point adjectival scale	Each domain 0-100	Brazilian, US English, Ukrainian
Skindex-17[94]	SRQL	Adolescents and adults with skin disease	1 mo	Symptoms (5), psychosocial (12)	5-Point adjectival scale	Symptoms: 0-10; psychosocial: 0-24	US English
Skindex-29[93]	SRQL	Adolescents and adults with skin disease	1 mo	Symptoms (10), emotions (7), functioning (12)	5-Point adjectival scale	Each domain 0-100	German, Italian, Polish, Spanish, UK English
Generic							
EQ5D-5d-5L[131]	Health state	Adolescents and adults	Today	Mobility (1), self-care (1), usual activities (1), pain/discomfort (1), anxiety depression (1), health today VAS	5-Point adjectival scale, 100 pt VAS	The 5 descriptive states are summarized with a 5-digit number that describes a health state	UK English, Chinese, Farsi, Greek, Hungarian
EQ5D-5d-3L[131,132]	Health state	Adolescents and adults	Today	Mobility (1), self-care (1), usual activities (1), pain/discomfort (1), anxiety and/or depression (1), health today VAS	3-Point adjectival scale	The 5 descriptive states are summarized with a 5-digit number that describes a health state	US English, Greek, Hungarian, Serbian, Swedish
EQ VAS[131,132]	Health state	Adolescents and adults	Today	Health VAS	0-100 VAS	0-100	US English, UK English, Greek, Hungarian, Serbian, Swedish, Chinese, Farsi

(continued)

Table 2. Characteristics of the Dermatology Specific and Generic Measures (continued)

PROM	Constructs	Target population	Recall period	(Sub)scale(s) (No. of items)	Response options	Range of scores	Language versions validate in psoriasis
PRISM[57]	Having illness	Adults with chronic illness	Currently	Distance between illness and self	Measured distance between 2 items	0-270	UK English
QOLS[85]	Quality of life	Adults	Not specified	1 Scale (16)	7-Point adjectival scale	16-112	Norwegian
SF-36[133]	HRQL	Adolescents and adults with skin disease	1 mo	Physical functioning (10), role limitations-physical (4), role limitations-emotional (3), energy (4), emotional well-being (5), social functioning (2), pain (2), general health (5)	Variable adjectival scales	0-100	US English, Spanish
WHOQOL-100[96]	Quality of life	Adults	Not specified	Physical health, psychological, level of independence, social relations, environment, spirituality/religion/personal beliefs (100)	5-Point adjectival scale	Each domain 0-100	US English

Abbreviations: DLQI, Dermatology Life Quality Index; DQOLS, Dermatology quality of life scales; EQ VAS, EuroQol visual analogue scale; FLQA, Freiburg Life Quality Assessment; EQ5D-5d-5L, EuroQol 5-dimensional questionnaire (5 levels of response); ISDL, Impact of Chronic Skin Disease on Daily Life; PRISM, Pictorial representation of Illness and self-measure; PROM, patient-reported outcome measure; QOLS, Quality of Life Scale; SF-36, 36-Item Short Form Survey; VAS, visual analogue scale; WHOQOL-100, World Health Organization Quality of Life.

validity studies. The content validity studies for the DLQI (UK English),[50] DLQI (US English),[82] and Skindex-29 (UK English)[50] were of adequate quality, whereas the content validity study for the QOLS (US English)[85] was of inadequate quality. Two SRQOL measures had sufficient overall content validity (DQOL [UK English][42] and Skindex-16 [US English][67]) with very low level of evidence. No generic PROMs had sufficient content validity.

Summaries of measurement properties are shown in eTables 2 and 3 in the Supplement. No studies evaluated measurement error or measurement invariance. Most PROMs were considered reflective, but PROMs with symptoms scores or questions about symptomatology (EQ-5D, IPBOD, NAPPAQOL, PsoLife, P-SIM, Psodisk, PQOL12, and PQOL41) were considered mixed because some symptoms-based questions act as causal indicators of HRQL (formative model). Although we assessed structural validity and internal consistency for these measures, the results may be affected by the mixed structure.

Among psoriasis-specific measures, structural validity was rated sufficient for 9 PROMs (IPSO-10 CTT [US English],[86] IPSO-11 Rasch [US English],[86] IPSO-11 [Italian],[106] NPQ10 [French],[45] NAPPAQOL [German, English, Danish, Japanese, Italian, and Spanish],[72] PQLQ [Turkish],[43] PsoLife [Spanish],[109] PSORIQoL [UK English, US English],[48,49] QualiPso [French][110]) and quality of evidence was high for IPSO-11 Rasch, IPSO-11, and PSORIQoL and moderate for the remaining 6 PROMs. Nine measures had insufficient structural validity (IBOP [French],[66] IPSO-16 [US English],[86] PDI [US English,[105] UK English,[103] Chinese,[80] Norwegian,[101] Persian,[65] Sinhala[111]], PLSI [UK English]). GRADE score was high for the IBOP [French and US English], IPSO-16 [US English], and the PDI [US English] and moderate for the remaining 6 PROMs. Seven psoriasis-specific PROMs (IPSO-11 Rasch [US English],[86] IPSO-11 [Italian],[106] NPQ10 [French],[45] NAPPAQOL [German, English, Danish, Japanese, Italian, and Spanish],[72] PsoLife [Spanish],[109] PSORIQOL [UK English,[48] US English[49]], and QualiPso [French][110]) had sufficient internal consistency with high-quality evidence. Internal consistency was insufficient for 3 measures (IPSO-10 CTT [US English],[86] IPSO-16 [US English],[86] and PQLQ [Turkish][43]), with all having a high GRADE score except the PQLQ (very low). Responsiveness was assessed for 7 measures.[46,47,64,104,109,113,118,120] The Psodisk (Italian)[120] and PLSI (US English)[104] had insufficient responsiveness with low and moderate GRADE scores, respectively.

For SRQL measures, 4 PROMs were found to have sufficient structural validity (DLQI [Chinese],[80] DLQI [Italian],[117] DLQI [Norwegian],[99] and Skindex-29 [German][56]). Level of evidence was high for the DLQI [Chinese] and moderate for the others. Four measures (DLQI [Chinese],[80] DLQI [Italian],[117] DLQI [Norwegian],[99] Skindex-16 [Ukrainian],[60] and the Skindex-29 [German][56] had high-quality evidence for sufficient internal consistency. Five SRQL PROMs (DLQI [US English],[87,107,114] DLQI [Danish],[38] DLQI [German],[37] DLQI [Spanish],[64,70] and Scalpdex [Italian])[84] had sufficient responsiveness with moderate level of evidence, except for Scalpdex, which had a high GRADE score.

For generic measures, no studies were identified evaluating structural validity. Internal consistency was assessed for 1 measure (WHOQOL-100)[62] and found to be sufficient with a high GRADE score. Responsiveness was assessed for 3 measures (SF-36 [US English],[107] EQ-5D-5L [Chinese; Index score],[52,58] and the EQ-5D-3L [US English; index score, VAS]),[107] which was sufficient with high GRADE scores for all 3.

Recommendations of PROMs Use in Psoriasis

Among all PROMs, only the IPSO 11 Rasch [US English] had sufficient evidence for an A recommendation (recommended for use). Six measures received a C rating (not recommended): IPSO-16 [US English], IPSO-10 CTT [US English], PDI [US English], DLQI [Moroccan], IBOP [French and US English], and DLQI [Hungarian]. These PROMs had high-quality evidence for an insufficient key measurement property. The remaining PROMs were category B. (eTable 4 in the Supplement)

Discussion

We identified 19 psoriasis-specific, 8 skin-specific, and 6 generic PROMs to assess HRQL in patients with psoriasis, along with trans-

Figure 2. Summary of Content Validity of Psoriasis-Specific Measures

	Overall content validity							
	Relevance		Comprehensiveness		Comprehensibility		Overall	
Instrument	Rating	Grade	Rating	Grade	Rating	Grade	Rating	Grade
Psoriasis specific								
EQ-5D-Pso (UK English)[47,132]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
EQ-5D-Pso (Hungarian)[27,47,132]	Inconsistent	Very low	Insufficient	High	Sufficient	High	Inconsistent	Moderate
I-BOP (French, US English)[66]	Sufficient	Very low	Insufficient	Very low	Inconsistent	Very low	Inconsistent	Very low
IPBOD (US English)[92]	Insufficient	Very low	Sufficient	Very low	Insufficient	Very low	Inconsistent	Very low
IPSO-16 (US English)[86]	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low
IPSO-10 CTT (US English)[86]	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low
IPSO-11 Rasch (US English)[86]	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low
NPQ10 (French)[45]	Insufficient	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
NAPPA-QoL (German, UK English)[72]	Inconsistent	Very low	Sufficient	Very low	Sufficient	Very low	Inconsistent	Very low
PDI (UK English)[40]	Sufficient	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
PDI (Norwegian)[40,101]	Sufficient	Moderate	Insufficient	Very low	Sufficient	Moderate	Inconsistent	Low
PLSI (US English)[104]	Inconsistent	Very low	Insufficient	Very low	Indeterminate[a]	Very low	Inconsistent	Very low
PQLQ (Turkish)[43]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
P-SIM[44]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
PSOdisk (US English, Italian)[78]	Sufficient	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
PSO-LIFE (Spanish)[109]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
PSORIQoL (UK English, Italian, and Dutch)[48]	Sufficient	Low	Insufficient	Very Low	Sufficient	Very low	Inconsistent	Very low
PsoriQOL (US English)[49]	Sufficient	Low	Insufficient	Very Low	Sufficient	Very low	Inconsistent	Very low
PQOL-12 (US English)[95]	Sufficient	Very Low	Insufficient	Very Low	Sufficient	Very low	Inconsistent	Very low
PQOL41 (US English)[95]	Sufficient	Very Low	Sufficient	Very Low	Sufficient	Very low	Sufficient	Very low
QLICD-PS (V2.0) (Chinese)[46]	Indeterminate[a]	Very Low	Indeterminate[a]	Very Low	Indeterminate[a]	Very low	Indeterminate[a]	Very low
QualiPso (French)[110]	Indeterminate[a]	Very Low	Sufficient	Very Low	Sufficient	Very low	Indeterminate[a]	Very low

EQ-5D-Pso indicates Psoriasis-specific EuroQol five-dimensional questionnaire; I-BOP, Individual Burden of Psoriasis; IPBOD, Inverse Psoriasis Burden of Disease; IPSO-16, Impact of Psoriasis Questionnaire (16 questions); IPSO-10 CTT, Impact of Psoriasis Questionnaire (10 questions, derived using Classic Test Theory); IPSO-11 Rasch Impact of Psoriasis Questionnaire (11 questions, derived using Rasch methods); NPQ10, Nail Psoriasis Quality of Life Scale; NAPPA-QoL, Nail Assessment in Psoriasis and Psoriatic Arthritis Quality of Life; PDI, Psoriasis Disability Index; PLSI, Psoriasis Life Stress Inventory; PQLQ, Psoriasis Quality of Life Questionnaire; P-SIM, Psoriasis Impact and Symptoms Measure; PSORIQoL; PQOL-12, Psoriasis Quality of Life (12 items); PQOL41, Psoriasis Quality of Life (41 items); QLICD-PS (V2.0), Psoriasis-specific Quality of Life Instruments for Chronic Diseases version number 2.

[a] The instrument form of the PROM was not available for reviewers to evaluate the content validity of the instrument.

lations for several of them. Evaluation of the measurement properties of these identified measures revealed a dearth of information regarding their quality, specifically in terms of key measurement properties such as content validity, structural validity, and internal

Figure 3. Summary of Content Validity of Dermatology-Specific and Generic Measures

	Overall content validity							
	Relevance		Comprehensiveness		Comprehensibility		Overall	
Instrument	Rating	Grade	Rating	Grade	Rating	Grade	Rating	Grade
Dermatology Specific								
DLQI (UK English)[41,50]	Inconsistent	Very low	Insufficient	High	Sufficient	High	Inconsistent	Moderate
EDLQI (US English)[41,82]	Inconsistent	Low	Insufficient	Very low	Sufficient	Moderate	Inconsistent	Very low
DQOLS (UK English)[42]	Sufficient	Very low	Insufficient	Very low	Sufficient	Very low	Sufficient	Very low
FLQA (German)[108]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
ISDL (Dutch)[97]	Insufficient	Very low	Sufficient	Very low	Indeterminate[a]	Very low	Inconsistent	Very low
Scalpex (US English)[91]	Sufficient	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
Skindex-16 (US English)[67,93]	Sufficient	Low	Sufficient	Very low	Sufficient	Very low	Sufficient	Very low
Skindex-17 (US English)[93,94]	Sufficient	Low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
Skindex-29 (UK English)[50,93]	Sufficient	Low	Inconsistent	Moderate	Sufficient	High	Inconsistent	Moderate
Skindex-29 (US English)[93]	Sufficient	Low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
Generic								
EuroQol (Dutch, UK English, Finnish, Norwegian, Swedish)[132]	Sufficient	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
PRISM (UK English)[57]	(1)	(1)	(1)	(1)	(1)	(1)	(1)	(1)
QOLS (US English)[29,85]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
SF-36 (US English)[133]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low
WHOQOL-100 (Multicentric)[96]	Inconsistent	Very low	Insufficient	Very low	Sufficient	Very low	Inconsistent	Very low

Cells marked as (1) indicate that these were unratable due to the design of the PROM. DLQI indicates Dermatology Life Quality Index; DQOLS, Dermatology quality of life scales; EQ5D-5d-5L, EQ5D-5d-3L, EuroQol 5-dimensional questionnaire (3 levels of response); EQ VAS, EuroQol 5-dimensional questionnaire (5 levels of response); EuroQol visual analogue scale; FLQA, Freiburg Life Quality Assessment; ISDL, Impact of Chronic Skin Disease on Daily Life; PRISM, Pictorial representation of Illness and self-measure; QOLS-N, Quality of Life Scale; SF-36, 36-Item Short Form Survey; SRQL, Skin-related Quality of Life; WHOQOL-100, World Health Organization Quality of Life.

[a] The instrument form of the PROM was not available for reviewers to evaluate the content validity of the instrument.

consistency. This gap in knowledge can be attributed to the fact that most measures were developed using validation criteria that differ from the current standards set by COSMIN. As a result, further validation studies in line with modern standards are needed to assist researchers and clinicians in selecting the most appropriate HRQL measures for psoriasis.

According to COSMIN standards (sufficient content validity, structural validity, and internal consistency), only 1 measure, the Rasch reduced version of the Impact of Psoriasis Questionnaire (IPSO-11 Rasch),[86] received an A recommendation for use. However, it is important to note that data were not available for reliability, construct validity, or responsiveness for this version (though there are data to support the construct validity of its parent measure, the IPSO-16). In addition, the evidence for content validity was of very low quality (ie, only based on reviewer ratings). Therefore, although the IPSO-11 Rasch met the COSMIN criteria to receive an A recommendation, there is a need for additional studies to confirm its content validity and other measurement properties. The PSORIQoL, NPQ10, and the NAPPAQOL had sufficient structural validity and internal consistency, but evidence supporting their content validity was limited. If further data were available to confirm the content validity of these measures, they could receive an A recommendation for use.

Among dermatology-specific measures, both the Skindex-16[67] and the DLQI[41] have received B recommendations for use, indicating their potential but requiring further validation. The US English version of Skindex-16 demonstrated sufficient content validity (very low quality), although data on its structural validity and internal consistency were not available. The DLQI had inconsistent evidence for content validity. Whereas Safikhani et al[82] concluded that the DLQI

included all relevant concepts, Paudyal et al[50] reported that the DLQI may not adequately capture the emotional effects experienced by individuals with psoriasis. However, it is important to acknowledge that the assessment of comprehensiveness is challenging because items that are strongly correlated may be deleted during measure development to improve feasibility. In addition, the high prevalence of not relevant responses on the DLQI raised concerns about its content validity and potential for bias when used among diverse populations.[51,116,122] Results regarding the structural validity of the DLQI varied across different language versions, with the UK English version showing insufficient structural validity. In contrast, studies showed that the DLQI [Spanish,[64,70] English US,[87,107,114] German,[37] and Danish[38]] was able to capture change in SRQL over time. Overall, these findings underscore the importance of additional validation studies for the various versions of the DLQI.

There was a lack of studies examining the content validity, structural validity, and internal consistency of generic HRQL measures such as the EQ-5D and SF-36 in the context of psoriasis. However, it is worth noting that the English versions of the EQ-5D-3L and SF-36 demonstrated high-quality evidence for sufficient responsiveness,[107] indicating their ability to detect changes in HRQL over time in this population. In particular, the SF-36 has shown promise in detecting clinically meaningful treatment-associated improvements in psoriasis and has demonstrated low evidence of ceiling effects, which means it can capture improvements even when patients are already functioning at a high level.[123] OMERACT (Outcome Measures in Rheumatology) has recognized the value of using generic HRQL measures alongside disease-specific measures because they capture different aspects of the effects of the disease.[124-127] Overall, these findings highlight the need for studies exploring the content validity, structural validity, and internal consistency of generic HRQL measures in the context of psoriasis to enhance their utility in clinical practice and research.

Limitations

It is possible that some studies were performed according to the standards outlined by COSMIN, but that these details were not included in the resulting publications. This issue may be particularly common among studies published prior to the COSMIN initiative start in 2005. Because only aspects of studies that were reported can be assessed, it is possible that we may underestimate the quality of the evidence for some of the examined PROMs. Another limitation is that several aspects of the COSMIN risk of bias checklist are somewhat subjective. To mitigate potential reviewer bias, we discussed and formalized assumptions for these situations a priori and created rubrics to improve consistency (see methodology for assessing comprehensiveness of PROMs, Supplement). Although the COSMIN framework has certain limitations, it offers a formal framework from which to assess the quality of PROM development and measurement properties.[128-130]

Although COSMIN primarily recommends that only 1 literature search is conducted using the following strategy: (1) construct, (2) population(s), (3) type of instrument(s), and (4) measurement properties, we used an alternative 2-stage strategy also described in the COSMIN manual by which we first identified all PROMs that have been used in patients with psoriasis (stage 1) and subsequently searched for validation studies for all PROMs identified in stage 1 (stage 2). Although we suspect that this strategy would yield similar results to the recommended approach described in the COSMIN manual, it is possible that important development, pilot, or validation studies were missed. In addition, because PROM development and validation work is an ongoing process, future updates to this review will be important to guide decisions on PROM use.

Conclusions

Most of the identified measures received a B recommendation for use, indicating their potential to be recommended but requiring further validation. Only the Rasch reduced IPSO-11 was found to be sufficiently valid with respect to the COSMIN standards. Therefore, additional research that follows modern psychometric standards would be highly beneficial for researchers and clinicians in their endeavor to choose the most suitable HRQL measure for patients with psoriasis.

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