

Systematic review of content and phrasing of patient-reported outcome measures used in patients with psoriasis



To the Editor: Psoriasis is associated with significant physical and psychological comorbidities, including cardiovascular disease, arthritis, and depression.¹ To capture this lived experience of psoriasis, patient-reported outcome measures (PROMs) are a valuable tool that can complement clinical assessment.² To inform choice of PROMs for use among patients with

psoriasis, this study sought to identify and describe the content captured by existing psoriasis PROMs.

PROMs assessing health-related quality of life among patients with psoriasis were identified by a systematic review (personal communication; PROSPERO registration: CRD42017075580).³ For each PROM item, content and phrasing (positive, negative, neutral) were evaluated.⁴ Each item was assigned 3 levels of coding (domain, subdomain, and health concepts) as informed by Patient-Reported Outcomes Measurement Information Systems.³

Table I. Domains, subdomains, and health concepts of patient-reported outcome measures for patients with psoriasis

Domain	Subdomain	Health concepts
59 Physical well-being	41 Symptom	Sensitive, extension, appearance, different, house work, bother, burn, brittle, atrophy, thin, strong, burn, sting, unpleasant, itchiness, soreness, scales, pain, constant, fissures, cracks, driving, dressing, grip, inconvenience, shedding, irritation, bleed, maceration, odor, socks, shoes, sleep, personal hygiene, sports, walk
	18 Functioning	
92 Psychological well-being	42 Body image	Anger, expectations, misfortune, annoyance, sad, appearance, stare, avoid, clothes, conceal, flakes, self-consciousness, self-confidence, stigmatization, thoughts, unclean, ugly, worry, disgust, disturb, embarrassment, shame, emotional well-being, enjoy life, frustration, helplessness, hide, impair, interfere, peace of mind, irritable, aggression, people, acceptance, exclusion, preoccupation, pride, control, unsightly, extension
	34 Distress	
	7 Anxiety	
	4 Depression	
	4 Anxiety/depression	
115 Social well-being	1 Functioning	Daily activities, leisure, affection, awkward, career, friends, relatives, intimacy, sexual activity, dating, pool, beach, gym, sunbathing, gardening, hairdresser, friction, difficulties, hesitant, public places, hide, clothes, meet others, contagious, interviews, distance, school, work, remarks, shaking hands, touch, travel, holiday, uncomfortable, criticism, visiting, withdrawn, reserved, work with hands, study
	7 Romantic relationship	
	7 Sexual functioning	
	1 Romantic/social relationship	
	28 Social relationship	
	23 Social isolation	
	3 Distress	
	2 Body image	
	1 Anxiety	
	1 Appearance	
1 Social well-being/psychological well-being	1 Sexual relationship	Social/psychological burden
	1 Functioning/distress	
13 Treatment	6 Expectations	Time, difficult, annoying, time consuming, expensive, money, not efficient, adverse effects, not satisfactory, problem
	4 Skin care	
	3 Cost	
4 Vitality	2 Functioning	Daily life, daily activities, health, impair, affect, stop
	2 Overall health	

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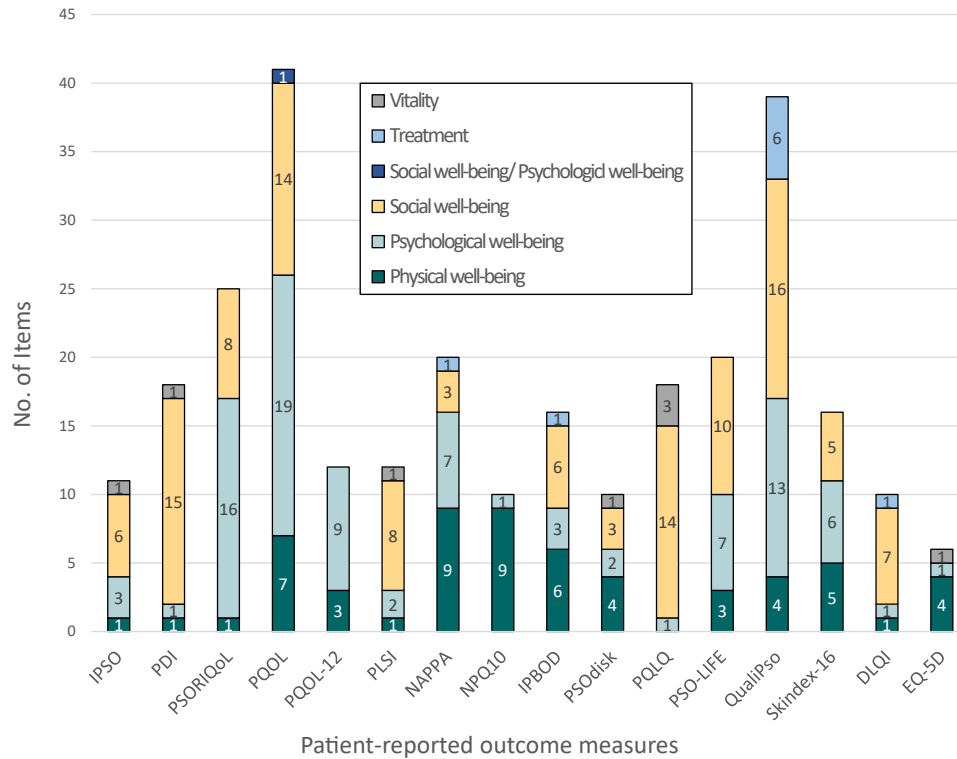


Fig 1. Content analysis of individual patient-reported outcome measures questionnaires for patients with psoriasis. *DLQI*, Dermatology life quality index; *EQ-5D*, EuroQol 5 dimension; *IPBOD*, Inverse Psoriasis Burden of Disease Questionnaire; *IPSO*, Impact of Psoriasis Questionnaire; *NAPPA*, Nail Assessment in Psoriasis and Psoriatic Arthritis; *NPQ10*, nail psoriasis quality of life scale; *PDI*, Psoriasis Disability Index; *PLSI*, Psoriasis Life Stress Inventory; *PQLQ*, Psoriasis Quality of Life Questionnaire; *PQOL*, Psoriasis Quality of Life Questionnaire; *PQOL-12*, Psoriasis Quality of Life Questionnaire-12; *PSO-LIFE*, psoriasis quality of life questionnaire; *PSORIQoL*, Psoriasis Index Quality of Life.

Coding was performed by 3 researchers (H.A.H., J.Y., J.S.B.) with iterative development of the codebook until all concepts were comprehensively described with inter-coder consensus. Data collection and analysis was performed with Microsoft Excel. This study did not require institutional review board approval.

Thirteen psoriasis-specific, 2 dermatology-specific, and 1 generic PROM were evaluated for a total of 284 items. Most items had negative phrasing and no items had positive phrasing (negative, $n = 227$, 79.9%; neutral, $n = 57$, 20.1%; positive, $n = 0$, 0.0%). Six PROMs contained exclusively negative phrasing (Psoriasis Disability Index, Psoriasis Index Quality of Life, Psoriasis Life Stress Inventory, nail psoriasis quality of life scale [NPQ10], psoriasis quality of life questionnaire [PSO-LIFE], Skindex-16).

Each item had an average of 2.28 (median 2) health concepts, with a total of 295 unique health concepts across PROMs. These health concepts were organized into 25 subdomains, with 5 overarching

domains (physical well-being, psychological well-being, social well-being, treatment, and vitality) (Table D). The most frequently captured domains were social well-being ($n = 115$, 40.5%) and psychological well-being ($n = 92$, 32.4%).

Differences were observed in the relative domains included in each PROM. Psoriasis Quality of Life, Inverse Psoriasis Burden of Disease Questionnaire, Psodisk, QualiPso, Skindex-16, and Dermatology life quality index most comprehensively covered identified domains, though no PROMs captured all 5 domains (Fig 1). Some PROMs had a relative emphasis on one domain; eg, Psoriasis Quality of Life-12 (75.0%, 9/12 items) and Psoriasis Index Quality of Life (64.0%, 16/25 items) emphasized psychological well-being, while Psodisk (44%, 4/9 items) relatively emphasized physical well-being.

In this study characterizing the content and phrasing in PROMs assessing health-related quality of life (HRQoL) among patients with psoriasis, while many common themes were identified, there were notable differences between PROMs. These

differences may influence which PROMs are most appropriate for different settings; for instance, if there is a focus on psychological well-being, the Psoriasis Quality of Life-12 and Psoriasis Index Quality of Life may be most applicable, whereas Psodisk may be better suited for physical well-being.

Notably, PROMs predominantly included negative phrasing. Since negative phrasing may adversely affect patients' understanding of psoriasis and themselves, it is important for PROM developers to be thoughtful and deliberate when considering whether to use positive or negative phrasing.⁵

This study was limited by qualitative design, including challenges with classifying items covering multiple health concepts. This was mitigated through review of each item by multiple reviewers and iterative codebook development.

PROMs provide valuable information to understand the lived experience of psoriasis, which can be used to better individualize management in clinical practice. This analysis provides a framework to guide clinicians and researchers for selecting which PROM is most relevant to their specific needs.

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Conflicts of interest

None disclosed.

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