

Patient-reported outcome (PRO) measures: brief description

Dermatology Life Quality Index (DLQI)

The DLQI is a skin-generic QoL questionnaire that includes ten items (e.g., Over the last week, how much has your skin affected any social or leisure activities?) to be answered in a 4-point Likert scale ranging from 0 (“not at all”/ “not relevant”) to 3 (“very much”). A total sum score ranging from 0 to 30 was computed, with higher scores indicating larger impairments. Dermatology Life Quality Index > 10 were considered as very/ extremely large impairments. In the study sample, the DLQI presented a Cronbach’s alpha of 0.92.

ItchyQoL

This pruritus-specific ItchyQoL includes 22 items (e.g., I need to scratch my itchy skin.) assessing symptoms, functioning, feelings, and self-perception, to be scored on a 5-point Likert scale ranging from 1 (“never”) to 5 (“all the time”). A total score was computed from the mean scores of the patients’ responses to all items, with higher scores representing more QoL impairments. A Cronbach’s alpha of 0.96 for the total score indicated good internal consistency for the current study.

Patient Benefit Index (PBI)

The PBI includes the Patient Needs Questionnaire (PNQ) and the Patient Benefits Questionnaire (PBQ), assessing, respectively, the importance of individual needs (e.g., “As a result of therapy, how important is it for you to be able to lead a normal everyday life?”) and the perceived benefits from treatment (e.g., “The current treatment has helped me to be able to lead a normal everyday life.”). Each questionnaire includes 25 items to be rated within a 5-point Likert scale ranging from 0 (“not at all”/ “does/ did not apply to me”) to 4 (“very”). The PBI was computed from the arithmetic mean of all rated PBQ items weighted by the relative importance of each corresponding PNQ items, ranging from 0 (no benefit) to 4 (maximal benefit). Good internal consistency was observed in the current sample, with a Cronbach’s alpha of 0.91 for the PNQ and 0.96 for the PBQ.

Patient Health Questionnaire (PHQ-2) and Generalized Anxiety Disorder (GAD-2)

The two-item PHQ and GAD questionnaires are ultra-brief screening tools for diagnosing and

monitoring depression (e.g., “Over the last 2 weeks, how often have you been bothered by any of the following problems? Little interest or pleasure in doing things”) and anxiety (e.g., “Over the last 2 weeks, how often have you been bothered by any of the following problems? Not being able to stop or control worrying”), respectively. For each questionnaire, the two items are scored in a four-point response scale ranging from 0 (“not at all”) to 3 (“nearly every day”). The total scores range from 0 to 6, with cut-off scores of ≥ 3 as indicators of clinically significant symptoms of depression/anxiety. In the current sample, Cronbach’s alphas of 0.89 were observed for both instruments.

Dysmorphic Concern Questionnaire (DCQ)

This screening instrument is composed of seven statements on one’s own concerns and behaviours related to slight/ perceived defect(s) in physical appearance (e.g., “Have you ever been very concerned about some aspect of your physical appearance?”), to be rated on a 4-point scale, in comparison to most people (0 = “not at all” to 3 = “much more than other people”). The total score was computed from the sum of all items, ranging from 0 to 21, whereby higher values indicate higher dysmorphic concerns and scores ≥ 11 represent significant concerns in bodily appearance. A Cronbach’s alpha of 0.87 suggested good reliability on the present study.

Perceived Stigmatization Questionnaire (PSQ)

This 21-item questionnaire assesses how a person perceives other’s behaviours directed toward him/ her, in terms of confused/ staring behaviour, absence of friendly behaviour and hostile behaviour (e.g., “People I don’t know act surprised or startled when they see me.”). The 5-point Likert response scale ranges from 1 (“never”) to 5 (“always”) and the total score was calculated from the mean score of the 21 items, with higher scores indicating higher levels of perceived stigmatisation. The Cronbach’s alpha for the total score on the current sample was 0.89.

Relationship and Sexuality Scale (RSS)

The RSS consists of 10 questions (e.g., “I am satisfied with the frequency of hugs and kisses between us.”) evaluating the impact of a disease and its treatments on sexual function, sexual frequency, and sexual fear. Response format used ordinal category scales ranging from 0 to 3 or from 0 to 4. The total score was computed from the sum of all 10 items, ranging from 0 to 36, whereby a higher score indicates higher problem level. In the present study, the Cronbach’s alpha was 0.81 for the total score.