Supplementary material to article by K. A. P. Meeuwis et al. "Genital Psoriasis Awareness Program: Physical and Psychological Care for Patients with Genital Psoriasis"

Appendix S1.

Outcome measures

Psoriasis severity. We used the Psoriasis Area and Severity Index (PASI) and Body Surface Area (BSA) to score the clinical severity of psoriasis in general. PASI assesses the severity of psoriasis on a scale ranging from 0 (no psoriasis) to 72 (severe psoriasis) (40) and BSA describes the percentage of surface skin affected by psoriasis ranging from 0 to 100%.

The clinical severity of genital psoriasis was assessed by the Investigators Global Assessment (IGA), SUM score and the Investigators Assessment of the extent of genital psoriasis (IA: surface of affected genital skin in cm²). The IGA score is depending on whether genital psoriasis is cleared (0), minimal (1), mild (2), moderate (3), severe (4) or very severe (5). The SUM score of genital psoriasis is calculated as the sum of the severity scores for erythema, desquamation and induration using the scoring system from the PASI (range 0–4 per item). The total SUM score ranges between 0 (no lesions) and 12 (very severe lesions).

Severity of genital psoriasis as experienced by the patient was measured by the Patient Global Assessment (PGA) ranging between clear (0) and severe (4), and visual analogue scales (VAS) on itch, pain and burning of genital skin (range 0–100).

(Sexual) quality of life

The 5-Dimension European QoL (EQ-5D) health survey was used to measure generic QoL. This survey has 2 parts. The first part assigns an index-score for the self-reported health state, including 5 domains. This index-score ranges between 0 and 1, where 0 represents death and 1 represents perfect health. Total scores were calculated by using the Dutch EQ-5D Tariff (41). When responses were missing for one or more of the domains, index scores were not calculated. The second part is a VAS, ranging between 0 (worst imaginable health state) and 100 (best imaginable health state).

The Dermatology Life Quality Index (DLQI) was used to assess the extent of the effect of psoriasis on daily living, with overall scores ranging from 0 ('not at all') to 30 ('very much'). In case of missing data, scores were calculated according to the manual (29).

Sexual QoL in female patients was measured by the Female Sexual Distress Scale (FSDS) (42). The total scores range from 0 to 48, with higher scores corresponding to higher levels of sexual distress. A score of \geq 15 is the recommended cut-off value to establish the presence of sexually related personal distress. With more than 10% of answers missing, questionnaires were excluded. The Sexual QoL Questionnaire for use in Men (SQoL-M) measures sexual QoL in men. Total scores range from 0 to 100, with higher scores corresponding to a better sexual QoL (30). According to the manual, with over 50% missing answers, the questionnaire was excluded from analysis.