Appendix SI

PILOT STUDY

Concept questionnaire

Briefly, the concept questionnaire starts with a description of HS and the primary lesion types. Subsequently, following the refined Hurley classification 3-step algorithm, 2 main questions are asked about the presence of the primary lesions: (1) sinus tracts, and (2) inflammatory nodules and/or abscesses. Patients can answer "yes" or "no". In case of a positive answer, additional questions (sub-questions) are asked corresponding to the refined Hurley classification 3-step algorithm (involved body locations, presence of inflammation, migratory or fixed lesions, and size of involved body location). Both primary questions are supported by brief information and prototypical photographs of the lesions.

Results

The patients' characteristics are shown in **STable I**.

The inter-rater agreement between patient's and physician's derived refined Hurley stages was 31.3% (5/16), and the inter-rater reliability showed an α of 0.150 (95% confidence interval (CI) –0.082–0.459) (**STable II**). Results regarding comparisons between the answer to the primary question about the presence of sinus tracts showed an inter-rater agreement of 50.0% and an α of –0.033 (95% CI –0.550–0.483).

Modifications made to concept questionnaire

Following the pilot study several modifications were applied to the concept questionnaire, resulting in the definitive questionnaire: the refined Hurley classification questionnaire for patients with HS (Appendix SII[1]). The order of the main questions was reversed: first the presence of abscesses/inflammatory nodules was asked, and secondly the presence of sinus tracts. The sub-questions remained the same, following the 3-step flowchart of the refined Hurley classification. Furthermore, the layout of the questionnaire was simplified and description of the symptoms and associated pictures were made more concise.

STable I. Patient characteristics pilot study cohort (*n*=16)

Age, years, mean±SD	35.5±12.5
Female sex, *n* (%)	11 (68.8)
BMI, kg/m^2, mean±SD	28.3±5.0
Smoking status, *n* (%)	
Non-smoker	1 (6.3)
Ex-smoker	6 (37.5)
Current smoker	9 (56.3)
Refined Hurley classification stage, according to physician, *n* (%)	
Refined Hurley IA	8 (50)
Refined Hurley IB	0 (0)
Refined Hurley IC	2 (12.5)
Refined Hurley IIA	2 (12.5)
Refined Hurley IIB	2 (12.5)
Refined Hurley IIC	1 (6.3)
Refined Hurley III	1 (6.3)

BMI: body mass index; SD: standard deviation.

STable II. Results concept questionnaire (*n* = 16)

	Inter-rater agreement %	Inter-rater reliability α	95% confidence interval
Derived refined Hurley stage	31.3	0.150	–0.082–0.459
Presence of inflammatory nodules/ abscesses	43.8	–0.130	–0.632–0.373
Presence of sinus tracts	50.0	–0.033	–0.550–0.483