Appendix S1.

Material and methods

Study design and population

A cross-sectional non-interventional study using a web-based questionnaire survey was conducted to collect patient-reported data. The recruitment of participants and dissemination of the web-based questionnaire surveys were conducted using a panel owned and operated by Rakuten Insight Co., Ltd. The Rakuten Panel is a digital platform, where 9.5 million Japanese users of their online services, including multiple financial services and e-commerce entities, are registered (https://insight.rakuten.co.jp/member/panel/). Prior to data collection, the study methodology, including the web-based questionnaire, was approved by an independent IRB (Institutional Review Board of Medical Corporation Incorporated Foundation Tentakai Team Medical Clinic (Registration Number: 2022-10)).

The survey invitations were sent to the registered Rakuten Panel users, and over 27,000 individuals responded to the web-based questionnaire. Individuals who met the following criteria based on self-reporting were included, specifically those who (i) met all 3 self-diagnosis criteria: a) presence of nodules (inflamed or noninflamed), sinus tracts (inflamed or noninflamed), follicular papules/pustules (folliculitis), abscesses, or scarring (atrophic, mesh-like, red, hypertrophic, linear, or bridged), b) a minimum of two clinical signs in two different areas, including the axilla, genitofemoral area, perineum, gluteal area, and female infra-mammary area (under or between breasts), and c) recurrent painful or suppurating lesions 2 or more times within 6 months, (ii) were aged 16 years or older at screening, and (iii) were willing and able to provide informed consent. The self-diagnosis criteria for hidradenitis suppurativa (HS) used in this study were locally adapted based on the English version of the self-diagnosis criteria (1) and modified in accordance with the diagnosis criteria published by the Japanese Dermatological Association (2) which is a region-adapted version of the European Union S1 guidelines with an additional histopathological criterion (3). The back translation of the locally adapted version of the self-diagnosis criteria of HS was conducted by a researcher in the field with native language ability in English and Japanese. The similarity and relevance of the back-translated sentences with the original sentences (1) were confirmed by a separate researcher in the field with native language ability in English and Japanese. Eligibility screening for self-diagnosed patients with HS was facilitated by showing illustrations of HS-related clinical signs (Fig. S4) to help participants visually comprehend clinical signs of HS. Individuals who met the following criteria were excluded: those who (i) had been diagnosed with HS by a physician or (ii) did not answer all questions. As a result, 400 participants with self-diagnosed HS were included in the analysis. Before the main survey, a preliminary survey was

conducted among 1,000 individuals who were randomly selected from registered Rakuten Panel users to ensure the feasibility of the study using the eligibility criteria.

Data collection

All data were collected by the web-based self-administered questionnaire. Skin-specific quality of life (QOL) was assessed by the Dermatology Life Quality Index (4, 5).

HS-specific QOL was assessed by the Hidradenitis Suppurativa Quality of Life (HiSQOL) instrument (6). The HiSQOL is a validated, 17-item instrument designed to assess HS-specific health-related QOL from symptom-, psychosocial-, and activities-adaptation-related aspects, and has a 7-day recall period. Details of the scoring methods are described in a previous study (6). The original HiSQOL questionnaire was translated from English into Japanese, and language validation was performed in accordance with the ISPOR guidelines (7).

General QOL was assessed by the short form 36-item health survey version 2 (SF-36v2), which consists of 8 dimensions, including physical functioning, role physical, role emotional, vitality, mental health, social functioning, bodily pain, and general health status (8). A T-score of each SF-36v2 dimension was calculated using norm-based scoring, where the scores were adjusted to the national standard values for Japan in 2017 developed by i-Hope International (Kyoto, Japan), with a mean ± standard deviation of 50 ± 10 points (9). Z-tests were performed for each SF-36v2 dimension to compare the mean scores of each SF-36v2 dimension in participants with self-diagnosed HS and the national standard scores. The Z-tests were 2-tailed, and p-values of <0.05 were considered statistically significant.

The effects of HS on the ability to work and perform daily activities were assessed by the Work Productivity and Activity Impairment Questionnaire: Hidradenitis Suppurativa (10).

Symptom severity was assessed using the Hidradenitis Suppurativa Symptom Assessment (11) and Patient Global Impression of Severity instruments (12). Sociodemographic characteristics and health-related information were also collected.

Statistical methods

Descriptive statistics were used to summarize the continuous variables through means and standard deviations and categorical variables through counts and percentages per category. All statistical analyses were performed using R statistical software version 4.1.2 (R Foundation for Statistical Computing, Vienna, Austria).

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