SHORT COMMUNICATION

The Disease Burdens of Self-diagnosed Hidradenitis Suppurativa Patients in Japan: A Cross-sectional Web-based Survey

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Submitted Dec 1, 2023. Published after revision Jul 1, 2024
Published Aug 23, 2024. DOI: 10.2340/actadv.v104.32746. Acta Derm Venereol 2024; 104: adv32746.

Hidradenitis suppurativa (HS) is a chronic skin condition characterized by painful inflammatory nodules, abscesses, fistulas, and scarring (1). In Japan, the prevalence of HS, estimated from health insurance claims, is notably low at 0.0039% (2,921 patients) (2), contrasting with higher rates in Europe (1.0–4.1%), the United States (0.1–0.2%), Taiwan (0.11%), and Korea (0.06%) (3). However, the prevalence of Japanese HS patients is likely an underestimate due to potential misdiagnosis and underdiagnosis (4). HS imposes a significant disease burden, with Japanese patients experiencing more severe symptoms compared with their Western counterparts and reduced quality of life (QOL) (5–7). The burden may be even greater for patients with undiagnosed HS, as the average delay in diagnosis is approximately 10 years (8, 9). Prolonged diagnostic delays exacerbate symptoms and increase the likelihood of requiring surgical interventions (9). While previous European studies have highlighted depression and low QOL among self-diagnosed HS patients (10, 11), the situation among Japanese self-diagnosed patients remains unclear. Therefore, this study aims to provide a comprehensive understanding of the disease burden among undiagnosed HS patients through a large-scale web survey in Japan.

MATERIALS AND METHODS

A cross-sectional non-interventional study using a web-based, self-administered questionnaire survey was conducted with self-diagnosed HS patients and patient-reported data were collected. We recruited 400 participants and conducted surveys using Rakuten Insight® panel research (https://insight.rakuten.com/). Invitations were sent to registrants, and those who met the criteria were enrolled. Further details regarding the study participants, data collection, and statistical methods can be found in Appendix S1.

RESULTS

The feasibility assessment suggested a prevalence estimate of self-diagnosed HS at 0.9% (95% CI, 0.4–1.7%; Fig. S1). The sociodemographic and clinical profiles of the 400 participants with self-diagnosed HS are summarized in Tables SI **and** SII. Participants were primarily middle-aged (mean age: 46.5 ± 13.2 years), male (67.5%), and of normal weight (63.0%; mean BMI: 23.4 ± 4.6 kg/m^2). Skin symptom onset averaged 13.7 ± 14.4 years, with 47.8% reporting symptoms for over 10 years. Affected areas included the head (36.0%), chest (27.5%), axillae (42.2%), abdomen (32.8%), back (41.0%), gluteal region (46.0%), hip-joint/groin (34.2%), and pubic region/anus (19.0%). In addition, 139 participants (34.8%) reported using analgesics, and the mean duration of analgesics use was 8.0 ± 10.7 years. Seventy participants (17.5%) had a family history of HS. Dermatology Life Quality Index (DLQI) scores averaged 9.9 ± 7.4 (Table SIII). The majority reported moderate to extremely large impacts on QOL due to skin symptoms (Fig. S2). High DLQI scores were positively correlated with symptom severity (adjusted odds ratio 2.05, 95% CI 1.56–2.69: Table SIV). The Hidradenitis Suppurativa Quality of Life (HiSQOL) results revealed mean scores of 21.7 ± 18.2 (Table SV). HS had a significant impact on walking (10.3%), exercising (13.8%), sleeping (21.0%), and sexual activities (8.8%). Participants were significantly impacted by HS-related pain and itch (Tables SV and SVI). The short form 36-item health survey version 2 (SF-36v2) scores were significantly lower across all dimensions compared with the 2017 national standard population (Fig. S3). The Work Productivity and Activity Impairment Questionnaire: Hidradenitis Suppurativa (WPAI: HS) findings showed reductions in working time (8 ± 16%), work effectiveness (29 ± 20%), overall work productivity (37 ± 25%), and daily activity (29 ± 20%) due to HS symptoms (**Table I**). Current medication use and treatment satisfaction indicated that 81.0% reported using a medication (Table SVII). Among those who used medication, 191 participants (59.0%) reported they were not satisfied with their current medication. Seventy participants (17.5%) reported over-the-counter medication use.

DISCUSSION

Our study was the first large-scale web-survey study among self-diagnosed HS patients in Japan and was the

Table I. Work productivity and activity impairment among participants with self-diagnosed hidradenitis suppurativa

	n	Mean (SD)
Absenteeism, %	285	8 (16)
Presenteeism, %	274	29 (20)
Work productivity loss, %	274	37 (25)
Activity impairment, %	400	29 (20)

SD: standard deviation.

first survey in the world to assess disease burden among only self-diagnosed HS patients without a physician diagnosis. This study provides clinical evidence that confirms and specifies the various disease burdens suffered by patients with undiagnosed HS in Japan.

The Japanese version of the self-diagnosis criteria, which was used to identify the participants in this study, was developed based on the English version of the self-diagnosis criteria with modifications following the Japanese Dermatological Association's diagnosis criteria and the European Union S1 guidelines-based self-diagnosis study (1, 12, 13). Our feasibility assessment suggested a prevalence estimate of 0.9%, contrasting starkly with previously reported figures in Japan (0.0039%) (2). The low prevalence of HS previously reported in Japan may result from misdiagnosis and underdiagnosis due to poor recognition among physicians and the reluctance of patients to consult medical professionals, possibly due to embarrassment (3).

Our findings on HS patient characteristics were consistent with previous studies in Japan, including features such as male preponderance, age at skin symptom onset, and body regions affected (in the gluteal region and axillae). In contrast, the proportion of self-diagnosed HS participants with a family history of HS was much higher in our study than previously reported in Japan (5, 14). Overall, our results suggest that the sociodemographic and clinical characteristics are generally comparable between physician-diagnosed and self-diagnosed HS in Japan.

When observing the QOL of HS patients in Japan, our study indicated diminished QOL among those with self-diagnosed HS. This is in agreement with prior studies in Japan (mean DLQI total score: 9.87) (6) and Europe (mean DLQI total scores: 10.5 to 13.2) among physician-diagnosed HS patients (7). Furthermore, our study reported an average HiSQOL score of 21.7, similar to reports from the United States and Denmark (mean scores: 28.98 and 26.92, respectively) (15). SF-36v2 scores from our study on self-diagnosed HS patients were not as low as in Japanese patients with physician-diagnosed HS (6), but were still lower across all dimensions compared with the general population. It was also found that pruritus severity in participants from our study was similar to physician-diagnosed HS patients, although the opposite trend was found regarding pain severity (15). Overall, there are both similarities and differences between physician- and self-diagnosed HS patients, and it is important to note that QOL scores were comparable between the 2 groups. Given that physician-diagnosed HS patients can receive appropriate care, it is crucial to facilitate the early diagnosis and subsequent treatment for self-diagnosed HS patients.

This study is the first to explore work and daily activity using the WPAI: HS instrument with Japanese patients. Previous research in Europe and North America found reduced work time, effectiveness, and overall productivity among physician-diagnosed HS patients (7). It was previously believed that self-diagnosed HS had less impact on work productivity compared with physician-diagnosed HS; however, our findings suggest that the levels of work impairment are similar in both groups.

Limitations from this study include using the Rakuten Panel, which may limit external validity, and the lack of response rate data. However, the wide panel reach allowed for increased recruitment and more meaningful insights ,which could have been limited by Japan's low HS prevalence (0.0039%) (2). No physician-diagnosed HS participants were found in the panel, making it impossible to make any direct comparisons. Some participants may have had folliculitis or acne, as HS symptoms on the head were reported. While efforts were made to ensure the validity and reliability of HiSQOL (15), there are no published data validating the Japanese version.

In conclusion, the prevalence of Japanese patients with self-diagnosed HS was higher than previously reported, and they indicated low QOL and satisfaction with their current medications. Locally adapted self-diagnostic tools may facilitate early diagnosis and appropriate treatments, which are crucial to alleviating the burden of HS.

ACKNOWLEDGEMENTS

AbbVie GK and the authors thank all registered Rakuten Panel users who responded to or participated in this study. Medical writing support was provided by Yuta Ishikawa, Louis Patrick Watanabe, and Todd D. Taylor of IQVIA Solutions Japan G.K., and the study was funded by AbbVie GK.

Funding sources: AbbVie GK funded this study and participated in the study design, research, analysis, data collection, interpretation of data, reviewing, and approval of the manuscript. All authors had access to the relevant data and participated in the drafting, review, and approval of this manuscript. No honoraria or payments were made for authorship.

IRB approval status: This study was approved by an independent Institutional Review Board (Registration Number: 2022-10).

Conflict of interest disclosures: K.H. has received grants, speaker honoraria, and consultancy fees from AbbVie GK; speaker honoraria and consultancy fees from Boehringer Ingelheim; grants and speaker honoraria from Eisai, Kyowa Kirin, Maruho, Mitsubishi Tanabe Pharma, Novartis Pharma, and Taiho Pharmaceutical; speaker honoraria from Janssen Pharmaceutical; and grants from Sun Pharma Japan. M.O. and K.M. are employees of AbbVie Inc. or AbbVie GK, and may hold AbbVie stock and/or stock options. T.A. has no conflicts of interest associated with this manuscript. T.N. has received grants, speaker honoraria, and/or consultancy fees regarding this manuscript from AbbVie GK and Eisai.

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