

# Racial and ethnic disparities of burden and feelings of stigmatization among patients with HS : a worldwide study

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## Rational

Hidradenitis suppurativa (HS) is a chronic, debilitating skin disease manifesting as recurrent, invalidating abscesses. In addition to causing intense pain, HS is commonly associated with disability, depression and anxiety, stigmatization and loss of self-esteem. Minimal attention has been given to racial and ethnic differences related to stigmatization in patients with HS. The objective of this study was to investigate and compare prevalence of stigmatization associated with vitiligo among different racial and ethnic population.

## Material and methods

An online survey was sent to a representative sample of the general population over 16 years of age in 20 countries around the world. As the study used anonymised data and did not involve clinical examination, institutional review board approval was not required. The questionnaire collected information on the patients' demographic and socio-demographic profiles. Patients with a physician-diagnosed HS were selected from the representative sample. Those who agreed to report their ethnic and racial origin and to rate their skin as one of the six Fitzpatrick skin phototypes were selected. In total, four groups were distinguished: African descent, with Fitzpatrick skin phototype (FSP) V-VI (AD), Caucasian descent with Fitzpatrick skin type 1-3 (C), East-Asian cohort from South Korea and Japan (EA) and Indian Cohort (I). The binary outcome was derived from the initial four-point scale, where the participant was considered to have answered 'yes' if the answer given was 1 for 'very often' or a 2 for 'sometimes' and 'no' if the answer given was 3 for 'rarely' or a 4 for 'never' to questions regarding the perception of stigmatization. Patients were considered to have feelings of stigmatization (FS) if they reported that they felt that they were ostracized or rejected by others and/or that they felt that they were looked at with disgust and/or that people avoided touching them and/or that people avoided approaching them because of their HS. A comparison of FS and patients without FS (non-FS) was used to evaluate predictors of FS among socio-demographic and clinical parameters; psychological impact on self-perception, relationships, daily life and social or professional life. Descriptive analyses using absolute and percentage frequencies were performed. For constant variables such as age, mean and median and estimates of dispersion (standard deviation, range) were calculated. The test of significance was two-sided and established at 5% ( $P < 0.05$ ). Z-test and Pearson's Chi-squared were performed to compare subjects with reported FS and those with non-FS. The t-test was used for percentage data and Pearson's Chi-squared for the variable 'location of residence' (Table 2). An alpha cut-off of  $P < 0.05$  was used for all significance tests.

## Results

From the 586 respondents (HSR), a population of 436 was selected, including 200 (45.8%) males and 236 (54.2%) females (mean age 36.6+/-11.6. min 18-76 years). There were 182 (41.7%) Caucasian descendants, 46 (10.6%) African descendants, 78 (17.9%) East Asian and (29.8%) 130 Indian respondents.

A total of 337 HS reported FS (77.3%), of which 259 (59.4%) felt ostracized or rejected by others, 254 (58.3%) felt looked at with disgust, 250 (57.3%) reported that people avoided touching them, and 244 (56.0%) reported that people avoided approaching them because of their HS. Caucasian descendants were less likely to experience feelings of stigma than African (65.4% vs 87%  $p < 0.05$ ), East Asian respondents (65.4% vs 78.2%  $p < 0.05$ ) and Indians (65.4% vs 90%  $p < 0.05$ ) (Table 1).

## Discussion

This is the first study to compare feelings of stigma between different ethnic and racial origins in patients living with HS. We demonstrated that Indian, East Asian and African respondents were more likely to experience feelings of stigma than Caucasian descendants. This might be explained by the greater importance given to physical appearance, the social pressure and frequent confusion of HS with leprosy in Indian subcontinent. Educational campaigns for the public and medical community may reduce stigma towards patients with HS.

Table 1 Association with feelings of stigmatization in the four ethnic and racial patient groups n (%)

	African descent n=46	East Asian respondents n=78	Caucasian descent n=182	Indian respondents n=130	Total
<i>HS with FS</i>	40( 87%)	61(78.2%)	119(65.4%)	117(90%)	337(77.3%)
<i>HS who felt ostracized or rejected by others</i>	25(54.3%)	49(62.8%)	93(51.1%)	92(70.8%)	259(59.4%)
<i>HS who felt looked at with disgust.</i>	32(69.6%)	47(60.3%)	85(46.7%)	90(69.2%)	254(58.3%)
<i>HS who reported that people avoided touching them</i>	19(41.3%)	43(55.1%)	89(48.9%)	99(76.2%)	250(57.3%)
<i>HS who reported that people avoided approaching them</i>	30(65.2%)	42(53.8%)	80(44%)	92(70.8%)	244(56.0%)

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