



**Factors associated with disease-specific life impact in patients with hidradenitis suppurativa: results from the Global VOICE project**

Journal:	<i>British Journal of Dermatology</i>
Manuscript ID	BJD-2022-0917.R3
Manuscript type:	Research Letter
Date Submitted by the Author:	n/a
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56	Keywords: Health services research, Hidradenitis suppurativa, Medical dermatology,
57	Outcome measurement, Qualitative research, Quality of life
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3 **Abbreviated Abstract**  
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5 Patients with hidradenitis suppurativa experience significant life impact related to their disease.  
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9 Younger age, Black race, high BMI, active smoking, flares, depression, anxiety, high comorbidity  
10 burden, disability, and difficult access to a dermatologist adversely influence life impact related to  
11 having hidradenitis suppurativa.  
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15 Attention to these factors, particularly modifiable ones, may reduce overall impact of disease.  
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For Peer Review

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52  
53  
54 **Manuscript word count: 746**

55 **Abstract word count: NA**  
56  
57  
58  
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1  
2  
3 **Tables: 1**

4 **Figures: 0**

5 **References: 3**

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42 **Falk G. Bechara**

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Dr. Daveluy reports personal fees from Abbvie, and research grants from Abbvie, InflaRx, UCB

**Véronique del Marmol**

Dr. del Marmol reports grants from ABBVIE, personal fees from SANOFI

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Dr. Delage has nothing to disclose.

**Solveig Esmann**

S. Esmann has nothing to disclose.

**Shani Fisher**

Dr. Fisher has nothing to disclose.

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Dr. Garg reports personal fees from AbbVie, Aclaris Therapeutics, Anaptys Bio, Aristeia Therapeutics, Boehringer Ingelheim, Bristol Myers Squibb, Incyte, InflaRx, Insmad, Janssen, Novartis, Pfizer, UCB, Union Therapeutics, and Viela Biosciences, and receives honoraria.

Dr Garg receives research grants from AbbVie, UCB and National Psoriasis Foundation. He is co-copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments for HS.

**Evangelos Giamarellos-Bourboulis**

Dr. Giamarellos-Bourboulis reports personal fees from Abbott CH, bioMérieux, UCB, Glaxo SmithKline, Swedish Orphan Biovitrum, and InflaRx GmbH. He has also received grants bioMerieux, Abbott CH, MSD Hellas, Horizon 2020 grants RISC inCOVID and ImmunoSep, InflaRx GmbH, Johnson & Johnson, Marie Curie Grant European Sepsis Academy and Horizon Health gran EPIC-ROWN-2.

**Amelia Glowaczewska**

Dr. Glowaczewska has nothing to disclose.

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20 Ingelheim. Dr Hamzavi has participated in clinical trials with Pfizer, Incyte, Abbvie,  
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30 Dr. Ingram reports a stipend as Editor-in-Chief of the British Journal of Dermatology and an authorship  
31 honorarium from UpToDate. He is a consultant for Boehringer Ingelheim, ChemoCentryx, Novartis and  
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44 personal fees from Incyte, grants and personal fees from InflaRx, grants from Janssen-Cilag, grants and  
45 personal fees from Novartis, grants and personal fees from UCB, grants from CSL Behring, grants from  
46 Regeneron, grants from Sanofi, personal fees from Kymera, personal fees from VielaBio. He is co-  
47 copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments  
48 for HS, as well as AKQOL and SCQOL for actinic keratosis and skin cancer respectively.  
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20 Novartis, and UCB; personal fees and grants from Incyte  
21  
22  
23

24 **Michelle A. Lowes**  
25

26 Dr. Lowes reports personal fees from Abbvie, Almirall, BSN Medical, Incyte, InflaRx, Janssen, Kymera,  
27 Phoenicis, Viela Bio, and XBiotech  
28  
29

30 **Lukasz Matusiak**  
31

32 Dr. Matusiak reports personal fees from Abbvie, Novartis, Pierre-Fabre, and Leo Pharma.  
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34

35 **Styliani Micha**  
36

37 None  
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39 **Robert Micheletti**  
40

41 Dr. Micheletti has nothing to disclose.  
42

43 **Dagfinn Moseng**  
44

45 Dr. Moseng has nothing to disclose.  
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47 **Haley Naik**  
48

49 Dr. Naik reports personal fees from 23andme, AbbVie, Medscape, DAVA Oncology, Boehringer  
50 Ingelheim. She received grant funding from Abbvie.  
51  
52

53 **Aude Nassif**  
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55 Dr. Nassif has nothing to disclose.  
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3 **Georgios Nikolakis**  
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5 Dr. Nikolakis reports personal fees from Mölnlycke.  
6

7 **So Yeon Paek**  
8

9 Dr. Paek reports personal fees from AbbVie, Janssen, Novartis, and Sanofi Genzyme.  
10

11 **Jose Pascual**  
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13 Dr. Pascual has nothing to disclose.  
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15 **Errol Prens**  
16

17 Dr. Prens has nothing to disclose.  
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19 **Sahil Rawal**  
20

21 Sahil Rawal has nothing to disclose.  
22

23 **Barry Resnik**  
24

25 Dr. Resnik reports personal fees from AbbVie  
26

27 **Hassan Riad**  
28

29 Dr. Riad has nothing to disclose.  
30

31 **Christopher Sayed**  
32

33 Dr. Sayed reports personal fees from Abbvie, Novartis, UCB, and Aclaris, other from InflaRx, other from  
34  
35 UCB, other from Chemocentryx, other from Incyte  
36  
37

38 **Saxon D. Smith**  
39

40 Dr. Smith reports personal fees from Abbvie, Novartis, UCB other from Abbvie, Novartis and UCB.  
41  
42

43 **Yssra Soliman**  
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45 Yssra Soliman has nothing to disclose.  
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47 **Andrew Strunk**  
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49 Andrew Strunk has nothing to disclose.  
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51 **Jacek Szepietowski**  
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3 Dr. Szepietowski reports personal fees from Abbvie, Novartis, Pierre-Fabre, Menlo Therapeutics, Sienna  
4 Biopharmaceuticals, Leo Pharma, Trevi, Sandoz, Sanofi Genzyme, Janssen-Cilag, Amgen, Galapagos,  
5 InflaRx, Regeneron, UCB.  
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7

8  
9 **Jerry Tan**

10  
11 Dr. Tan has a patent Copyright holder for HSQoL and HiSQoL with royalties paid.  
12

13  
14 **Linnea Thorlacius**

15  
16 Dr. Thorlacius reports personal fees from UCB, non-financial support from Abbvie and Janssen-Cilag,  
17 and grants from Regeneron. She is co-copyright holder of HiSQOL, Investigator Global Assessment and  
18 Patient Global Assessment instruments for HS.  
19

20  
21  
22 **Thrasylvoulos Tzellos**

23  
24 Dr. Tzellos reports grants and personal fees from Abbvie, grants and personal fees from UCB  
25

26  
27 **Hessel van der Zee**

28  
29 Dr. van der Zee reports personal fees from ABBVIE, personal fees from INFLARX, personal fees from  
30 NOVARTIS, personal fees from GALDERMA, personal fees from Incyte  
31

32  
33 **Bente Villumsen**

34  
35 B. Villumsen has nothing to disclose.  
36

37  
38 **Lanqi Wang**

39  
40 Dr. Wang has nothing to disclose.

41  
42 **Christos Zouboulis**

43  
44 Dr. Zouboulis reports personal fees from AbbVie, Bayer Healthcare, Boehringer-Ingelheim, Incyte,  
45 Inflarx, Janssen, Novartis, Regeneron, and UCB.  
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49  
50 **Prior Presentation:** There is no prior presentation of this work.

51  
52 **IRB statement:** This study was approved by the human subjects research committee at the Feinstein Institutes  
53 for Medical research at Northwell Health.

54  
55 **Keywords:** Global VOICE; Quality of Life; Impact; Hidradenitis suppurativa; HiSQOL  
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3 **Funding Sources:** none  
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6

7 **Abbreviations:**  
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9 Global Survey Of Impact and Healthcare Needs: Global VOICE  
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11 Hidradenitis suppurativa: HS  
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13 Hidradenitis suppurativa quality of life: HiSQOL  
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15 Quality of life: QOL  
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3 ~~Hidradenitis suppurativa (HS) is a potentially debilitating disease, and a~~ Among dermatologic  
4 conditions, ~~hidradenitis suppurativa (HS) it~~ may be associated with the largest impact on health and  
5 quality of life (QOL).<sup>1</sup> ~~To date, i~~ Impact and QOL in HS has largely been assessed by measures developed  
6 for general skin disease or physical and mental health. Information from HS patients on factors related to  
7 disease-specific life impact may support patient-centered strategies to optimize outcomes. The purpose of  
8 this study was to measure association between HS-specific QOL with demographic and clinical  
9 characteristics.  
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18 We performed a cross-sectional survey of HS patients at 27 institutions, mainly HS referral  
19 centers, in 14 different countries from October, 2017 through July, 2018 (Global Survey Of Impact and  
20 Healthcare Needs (Global VOICE)).<sup>1</sup> Life impact questions comprised the 17 items from the hidradenitis  
21 suppurativa quality of life (HiSQOL) measure, a validated disease-specific patient reported outcome that  
22 assesses symptoms, psychosocial impact, and activity restrictions. Response to each question is scored on  
23 a 5-point scale (0-4), with higher scores corresponding to worse QOL. Individual scores for each item are  
24 summed to create a total score ranging from 0 to 68.<sup>2</sup>  
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33 Univariable linear regression models were used to measure the bivariate relationship between  
34 each demographic and clinical variable and HiSQOL total score. Multivariable linear regression was used  
35 to assess the relationship between each variable and the HiSQOL total score while adjusting for all other  
36 covariates. Group differences and associations with QOL were expected to lessen when adjusting for flare  
37 frequency, since flare itself is a measure of disease activity and as such it is part of the process by which  
38 QOL is impaired. Accordingly, adjusting for flare frequency would reduce estimated differences in QOL  
39 between groups that differ in flare frequency. Multiple imputation by chained equations with 30  
40 imputations was used to account for missing data.  
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49 Among 1,927 participants completing the survey in clinic, 1,828 reported being diagnosed with  
50 HS by dermatologists, general practitioners, or other physicians~~a licensed healthcare provider~~ and were  
51 eligible for analysis. Demographic and clinical characteristics of participants have been described  
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3 previously.<sup>1,3</sup> Briefly, most patients were aged 18-40 years (62%), female (85%), either overweight or  
4 obese (79%), and nearly half were active smokers (44%).  
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7 Mean HiSQOL total score was 29.3 (SD 16.7), which corresponds to a moderate to very large  
8 effect in terms of established DLQI score bands.<sup>2</sup> Median total score was 28.5 (IQR 16-42). In bivariable  
9 analysis, factors associated with worse HS-related QOL included younger age, BMI >40.0, active  
10 smoking status, increasing flare frequency, depression and anxiety, higher number of comorbidities, high  
11 school education level or less, inability to work, and difficult or very difficult access to a dermatologist.  
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### 18 **(Table I)**

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20 In the multivariable adjusted linear regression model, differences in HiSQOL according to  
21 demographic and other factors were attenuated. **(Table I)** For example, adjusted mean HiSQOL  
22 difference between patients with BMI > 40 and BMI < 25.0 was reduced from 7.9 (95% CI 5.0, 10.8) to  
23 1.5 (95% CI -1.2, 4.1). Factors which remained strongly associated with HS-related QOL included  
24 disability ( $\beta=4.8$  vs. employed, 95% CI 2.7, 7.0), increasing number of comorbidities ( $\beta=1.5$ , 95% CI 0.8,  
25 2.2 per comorbidity) and very difficult access to a dermatologist ( $\beta=7.4$  vs. very easy, 95% CI 4.4, 10.4).  
26  
27 Increasing flare frequency was strongly associated with lower HS-related QOL and showed a graded  
28 relationship. In subgroup analysis of American and Canadian patients, Black race was associated with  
29 similar HS-related QOL [ $\beta=0.5$ , 95% CI -3.7, 4.8] before adjustment for covariates, and worse HS-related  
30 QOL  $\beta=5.9$ , 95% CI 2.0-9.7] after covariate adjustment, compared to white race. **(Table I)**  
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41 Limitations include enrolment of participants from HS referral clinics, which may overrepresent  
42 experiences of patients with more severe disease. Response denominator could not be calculated.  
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45 Thresholds for minimal clinically important differences in QOL by score are not yet established for  
46 HiSQOL.  
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49 In this Global VOICE analysis, patients with HS experienced high life impact related to their  
50 disease. Younger age, high BMI, active smoking, flares, depression, high comorbidity burden, disability,  
51 and difficult access to a dermatologist were associated with disease-related life impact in HS in  
52 unadjusted analysis. Age and access to a dermatologist had a graded relationship with life impact in  
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3 unadjusted analysis. Attenuation of regression coefficients after adjusting for flare frequency suggests that  
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5 increased flare frequency partially explains poorer disease-related QOL in certain groups. Black patients  
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7 with HS may experience worse disease-specific life impact compared to whites, and this topic warrants  
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9 further study. In the absence of highly satisfactory treatments,<sup>3</sup> attention to factors, particularly modifiable  
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11 ones, that correlate with poor QOL in HS patients may reduce overall impact of disease.  
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16 **Acknowledgements:** None  
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**References:**

1. Garg A, Neuren E, Cha D, Kirby JS, Ingram JR, Jemec GBE, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: results from the Global Survey of Impact and Healthcare Needs (VOICE) project. *J Am Acad Dermatol.* 2020;82(2):366-376.
2. Kirby JS, Thorlacius L, Villumsen B, Ingram JR, Garg A, Christensen KB, et al. The Hidradenitis Suppurativa Quality of Life (HiSQOL) score: development and validation of a measure for clinical trials. *Br J Dermatol.* 2020;183(2):340-348.
3. Midgett B, Strunk A, Akilov O, et al. Factors associated with treatment satisfaction in patients with hidradenitis suppurativa: results from the Global VOICE project [published online ahead of print, 2022 Jul 30]. *Br J Dermatol.* 2022;10.1111/bjd.21798. doi:10.1111/bjd.21798

**Table 1. Mean difference in HiSQOL score according to patient characteristics**

Variable	Unadjusted mean HiSQOL difference <sup>a</sup> (95% CI)	p-value	Adjusted mean HiSQOL difference <sup>a,b</sup> (95% CI)	p-value
<b>Delay in diagnosis</b> (per 1-yr.)	-0.02 (-0.11, 0.08)	.67	-0.04 (-0.14, 0.05)	.36
<b>Comorbidity count</b> (per 1-unit increase)	2.4 (1.6, 3.1)	<.001	1.5 (0.8, 2.2)	<.001
<b>Age (yrs.)</b>				
18-30	Ref.	Ref.	Ref.	Ref.
31-40	-0.2 (-2.4, 2.0)	.87	-0.3 (-2.2, 1.7)	.80
41-50	-1.8 (-4.1, 0.4)	.11	-0.9 (-3.1, 1.3)	.42
51-60	-6.2 (-9.0, -3.3)	<.001	-4.2 (-7.1, -1.4)	.004
61 +	-7.6 (-13.3, -1.9)	.009	-3.9 (-9.0, 1.2)	.13
<b>Sex</b> , male vs. female (ref.)	-3.7 (-6.0, -1.3)	.003	-1.0 (-3.2, 1.1)	.34
<b>BMI category</b>				
Underweight/Normal weight (BMI < 25)	Ref.	Ref.	Ref.	Ref.
Overweight (BMI 25.0-29.99)	3.0 (0.4, 5.7)	.03	1.6 (-0.7, 4.0)	.17
Obese 1 (BMI 30.0-34.99)	2.2 (-0.6, 5.0)	.12	-0.2 (-2.6, 2.2)	.87
Obese 2 (BMI 35.0-39.99)	3.6 (0.6, 6.6)	.02	0.2 (-2.4, 2.9)	.85
Obese 3 (BMI ≥ 40)	7.9 (5.0, 10.8)	<.001	1.5 (-1.2, 4.1)	.28
<b>Smoking status</b> (Ref. = Never)				
Former smoker	2.1 (-0.1, 4.3)	.06	1.1 (-0.9, 3.0)	.30
Active smoker	4.9 (2.8, 6.9)	<.001	1.7 (-0.2, 3.6)	.08
<b>Education</b>				
College/university degree	Ref.	Ref.	Ref.	Ref.
Graduate school degree	-1.2 (-3.7, 1.3)	.34	-0.7 (-2.9, 1.5)	.55
High school	5.8 (3.9, 7.7)	<.001	2.1 (0.4, 3.8)	.02
Less than high school	4.4 (0.7, 8.1)	.02	3.5 (0.1, 6.8)	.04
<b>Married/in relationship</b> , Ref = No	-0.7 (-2.6, 1.1)	.42	-0.5 (-2.1, 1.1)	.52
<b>Employment</b> (Ref. = Employed)				
Not looking for work or Retired	1.6 (-0.9, 4.1)	.21	0.9 (-1.4, 3.1)	.45
Unemployed	2.8 (-0.1, 5.6)	.06	0.5 (-2.0, 3.1)	.67
Disabled	9.5 (7.2, 11.8)	<.001	4.8 (2.7, 7.0)	<.001
<b>Main physician for HS is a dermatologist</b> , Yes vs. No (ref.)	-2.0 (-3.7, -0.3)	.02	0.4 (-1.2, 2.0)	.62
<b>Access to a dermatologist</b>				
Very easy	Ref.	Ref.	Ref.	Ref.
Easy	0.8 (-1.9, 3.5)	.57	0.7 (-1.7, 3.2)	.56
Neutral	2.2 (-0.5, 5.0)	.11	2.1 (-0.4, 4.6)	.10
Difficult	5.4 (2.7, 8.2)	<.001	4.7 (2.2, 7.2)	<.001
Very difficult	11.8 (8.6, 15.0)	<.001	7.4 (4.4, 10.4)	<.001
<b>Depression diagnosis</b> , Ref = No	7.8 (6.1, 9.5)	<.001	3.1 (1.2, 4.9)	<.001
<b>Anxiety diagnosis</b> , Ref = No	6.6 (4.8, 8.3)	<.001	1.5 (-0.3, 3.4)	.10
<b>Flare frequency</b>				
Every 6 months	Ref.	Ref.	Ref.	Ref.
Every 3 months	4.5 (0.7, 8.4)	.02	3.6 (-0.2, 7.3)	.06
Monthly	11.7 (8.5, 14.9)	<.001	10.2 (7.1, 13.3)	<.001
Weekly	18.8 (15.5, 22.1)	<.001	15.5 (12.3, 18.7)	<.001
Daily	24.6 (21.3, 27.9)	<.001	20.6 (17.3, 23.9)	<.001

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3 a – Mean difference in HiSQOL total score compared to the reference group. Higher HiSQOL scores  
4 correspond to worse QOL impairment. Accordingly, negative mean differences imply better QOL  
5 compared to the reference group, and positive mean differences imply worse QOL compared to the  
6 reference group.  
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9 b – Derived from a multiple linear regression model including all variables in the table as predictors. No  
10 variable selection procedure was performed.  
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For Peer Review

**Title: Factors associated with disease-specific life impact in patients with hidradenitis suppurativa: results from the Global VOICE project**

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54 **Manuscript word count: 746**

55 **Abstract word count: NA**  
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3 **Tables: 1**

4 **Figures: 0**

5 **References: 3**

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24 **Conflict of Interest / Financial Disclosures:**

25  
26 **Oleg Akilov**

27  
28 Dr. Akilov has nothing to disclose.

29  
30 **Afsaneh Alavi**

31  
32 Dr. Alavi reports personal fees from Abbvie, Boehringer Ingelheim, Janssen, InflaRx, Kymera, Novartis  
33 and UCB. She is a principal investigator for BI and Processa.

34  
35  
36  
37 **Christine Ardon**

38  
39 Dr. Ardon has nothing to disclose.

40  
41 **Falk G. Bechara**

42  
43 Dr. Bechara reports grants from AbbVie, Boehringer Ingelheim, Novartis, Inflarx, Janssen, and UCB

44  
45 **Arnon D. Cohen**

46  
47 Prof. Arnon Cohen received research grants or served as a consultant, advisor, speaker and safety board  
48 chairperson to AbbVie, Amgen, Boehringer Ingelheim, Dexcel pharma, Janssen, Lilly, Neopharm,  
49 Novartis, Perrigo, Pfizer, Rafa, and Samsung

50  
51  
52  
53 **Steven Cohen**

54  
55 Dr. Cohen reports grants from Abbvie Pharmaceuticals, and personal fees from Verrica Pharmaceuticals

**Steven Daveluy**

Dr. Daveluy reports personal fees from Abbvie, and research grants from Abbvie, InflaRx, UCB

**Véronique del Marmol**

Dr. del Marmol reports grants from ABBVIE, personal fees from SANOFI

**Maia Delage**

Dr. Delage has nothing to disclose.

**Solveig Esmann**

S. Esmann has nothing to disclose.

**Shani Fisher**

Dr. Fisher has nothing to disclose.

**Amit Garg**

Dr. Garg reports personal fees from AbbVie, Aclaris Therapeutics, Anaptys Bio, Aristeia Therapeutics, Boehringer Ingelheim, Bristol Myers Squibb, Incyte, InflaRx, Insmad, Janssen, Novartis, Pfizer, UCB, Union Therapeutics, and Viela Biosciences, and receives honoraria.

Dr Garg receives research grants from AbbVie, UCB and National Psoriasis Foundation. He is co-copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments for HS.

**Evangelos Giamarellos-Bourboulis**

Dr. Giamarellos-Bourboulis reports personal fees from Abbott CH, bioMérieux, UCB, Glaxo SmithKline, Swedish Orphan Biovitrum, and InflaRx GmbH. He has also received grants bioMerieux, Abbott CH, MSD Hellas, Horizon 2020 grants RISC inCOVID and ImmunoSep, InflaRx GmbH, Johnson & Johnson, Marie Curie Grant European Sepsis Academy and Horizon Health gran EPIC-ROWN-2.

**Amelia Glowaczewska**

Dr. Glowaczewska has nothing to disclose.

**Noah Goldfarb**

1  
2  
3 Dr. Goldfarb participates in clinical trials with Abbvie, Pfizer, Chemocentryx, and Balter Medical and has  
4 received personal fees from Novartis.  
5

6  
7 **Elena Gonzalez Brant**  
8

9 Dr. Gonzalez Brant has nothing to disclose.  
10

11  
12 **Øystein Grimstad**  
13

14 Dr. Grimstad has nothing to disclose.  
15

16  
17 **Iltefat Hamzavi**  
18

19 Dr. Hamzavi reports personal fees from AbbVie, Pfizer, UCB, Janssen, Incyte, Novartis Boehringer  
20 Ingelheim. Dr Hamzavi has participated in clinical trials with Pfizer, Incyte, Abbvie,  
21

22  
23 **Rosalind Hughes**  
24

25 Dr. Hughes has nothing to disclose.  
26

27  
28 **John R. Ingram**  
29

30 Dr. Ingram reports a stipend as Editor-in-Chief of the British Journal of Dermatology and an authorship  
31 honorarium from UpToDate. He is a consultant for Boehringer Ingelheim, ChemoCentryx, Novartis and  
32 UCB Pharma and has served on advisory boards for Insmmed, Kymera Therapeutics and Viela Bio, all in  
33 the field of hidradenitis suppurativa (HS). He is co-copyright holder of HiSQOL, Investigator Global  
34 Assessment and Patient Global Assessment instruments for HS.  
35  
36  
37  
38

39  
40 **Gregor Jemec**  
41

42 Dr. Jemec reports grants and personal fees from Abbvie, personal fees from Coloplast, personal fees from  
43 Chemocentryx, personal fees from LEO pharma, grants from LEO Foundation, grants from Afyx,  
44 personal fees from Incyte, grants and personal fees from InflaRx, grants from Janssen-Cilag, grants and  
45 personal fees from Novartis, grants and personal fees from UCB, grants from CSL Behring, grants from  
46 Regeneron, grants from Sanofi, personal fees from Kymera, personal fees from VielaBio. He is co-  
47 copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments  
48 for HS, as well as AKQOL and SCQOL for actinic keratosis and skin cancer respectively.  
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56  
57 **Qiang Ju**  
58  
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60

1  
2  
3 Dr. Ju has nothing to disclose.  
4

5 **Naomi Kappe**  
6

7 Dr. Kappe has nothing to disclose.  
8

9 **Brian Kirby**  
10

11 Dr. Kirby has been a paid consultant and/ or clinical trial investigator and /or received department  
12 research funds from Abbvie, Almirall, Astra-Zeneca, Amgen, BMS, Celgene, Eli Lilly, Janssen, Leo,  
13 Merck, Moonlake, Novartis, Sanofi and UCB.  
14  
15  
16

17 **Joslyn Kirby**  
18

19 Dr. Kirby reports personal fees from AbbVie, Bayer, ChemoCentryx, CSL Behring, Janssen, Moonlake,  
20 Novartis, and UCB; personal fees and grants from Incyte  
21  
22  
23

24 **Michelle A. Lowes**  
25

26 Dr. Lowes reports personal fees from Abbvie, Almirall, BSN Medical, Incyte, InflaRx, Janssen, Kymera,  
27 Phoenicis, Viela Bio, and XBiotech  
28  
29

30 **Lukasz Matusiak**  
31

32 Dr. Matusiak reports personal fees from Abbvie, Novartis, Pierre-Fabre, and Leo Pharma.  
33  
34

35 **Styliani Micha**  
36

37 None  
38

39 **Robert Micheletti**  
40

41 Dr. Micheletti has nothing to disclose.  
42

43 **Dagfinn Moseng**  
44

45 Dr. Moseng has nothing to disclose.  
46

47 **Haley Naik**  
48

49 Dr. Naik reports personal fees from 23andme, AbbVie, Medscape, DAVA Oncology, Boehringer  
50 Ingelheim. She received grant funding from Abbvie.  
51  
52

53 **Aude Nassif**  
54

55 Dr. Nassif has nothing to disclose.  
56  
57  
58  
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2  
3 **Georgios Nikolakis**  
4

5 Dr. Nikolakis reports personal fees from Mölnlycke.  
6

7 **So Yeon Paek**  
8

9 Dr. Paek reports personal fees from AbbVie, Janssen, Novartis, and Sanofi Genzyme.  
10

11 **Jose Pascual**  
12

13 Dr. Pascual has nothing to disclose.  
14

15 **Errol Prens**  
16

17 Dr. Prens has nothing to disclose.  
18

19 **Sahil Rawal**  
20

21 Sahil Rawal has nothing to disclose.  
22

23 **Barry Resnik**  
24

25 Dr. Resnik reports personal fees from AbbVie  
26

27 **Hassan Riad**  
28

29 Dr. Riad has nothing to disclose.  
30

31 **Christopher Sayed**  
32

33 Dr. Sayed reports personal fees from Abbvie, Novartis, UCB, and Aclaris, other from InflaRx, other from  
34  
35 UCB, other from Chemocentryx, other from Incyte  
36  
37

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40 Dr. Smith reports personal fees from Abbvie, Novartis, UCB other from Abbvie, Novartis and UCB.  
41  
42

43 **Yssra Soliman**  
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45 Yssra Soliman has nothing to disclose.  
46

47 **Andrew Strunk**  
48

49 Andrew Strunk has nothing to disclose.  
50

51 **Jacek Szepietowski**  
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2  
3 Dr. Szepietowski reports personal fees from Abbvie, Novartis, Pierre-Fabre, Menlo Therapeutics, Sienna  
4 Biopharmaceuticals, Leo Pharma, Trevi, Sandoz, Sanofi Genzyme, Janssen-Cilag, Amgen, Galapagos,  
5 InflaRx, Regeneron, UCB.  
6  
7  
8

9  
10 **Jerry Tan**

11 Dr. Tan has a patent Copyright holder for HSQoL and HiSQoL with royalties paid.  
12

13  
14 **Linnea Thorlacius**

15 Dr. Thorlacius reports personal fees from UCB, non-financial support from Abbvie and Janssen-Cilag,  
16 and grants from Regeneron. She is co-copyright holder of HiSQOL, Investigator Global Assessment and  
17 Patient Global Assessment instruments for HS.  
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22 **Thrasylvoulos Tzellos**

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24  
25

26  
27 **Hessel van der Zee**

28 Dr. van der Zee reports personal fees from ABBVIE, personal fees from INFLARX, personal fees from  
29 NOVARTIS, personal fees from GALDERMA, personal fees from Incyte  
30  
31

32  
33 **Bente Villumsen**

34 B. Villumsen has nothing to disclose.  
35  
36

37  
38 **Lanqi Wang**

39 Dr. Wang has nothing to disclose.  
40

41  
42 **Christos Zouboulis**

43 Dr. Zouboulis reports personal fees from AbbVie, Bayer Healthcare, Boehringer-Ingelheim, Incyte,  
44 Inflarx, Janssen, Novartis, Regeneron, and UCB.  
45  
46  
47  
48

49 **Prior Presentation:** There is no prior presentation of this work.  
50

51 **IRB statement:** This study was approved by the human subjects research committee at the Feinstein Institutes  
52 for Medical research at Northwell Health.  
53

54 **Keywords:** Global VOICE; Quality of Life; Impact; Hidradenitis suppurativa; HiSQOL  
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**Funding Sources:** none

**Abbreviations:**

Global Survey Of Impact and Healthcare Needs: Global VOICE

Hidradenitis suppurativa: HS

Hidradenitis suppurativa quality of life: HiSQOL

Quality of life: QOL

For Peer Review



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3 Among dermatologic conditions, hidradenitis suppurativa (HS) may be associated with the largest  
4 impact on health and quality of life (QOL).<sup>1</sup> Impact and QOL in HS has largely been assessed by  
5 measures developed for general skin disease or physical and mental health. Information from HS patients  
6 on factors related to disease-specific life impact may support patient-centered strategies to optimize  
7 outcomes. The purpose of this study was to measure association between HS-specific QOL with  
8 demographic and clinical characteristics.  
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15 We performed a cross-sectional survey of HS patients at 27 institutions, mainly HS referral  
16 centers, in 14 different countries from October, 2017 through July, 2018 (Global Survey Of Impact and  
17 Healthcare Needs (Global VOICE)).<sup>1</sup> Life impact questions comprised the 17 items from the hidradenitis  
18 supplicative quality of life (HiSQOL) measure, a validated disease-specific patient reported outcome that  
19 assesses symptoms, psychosocial impact, and activity restrictions. Response to each question is scored on  
20 a 5-point scale (0-4), with higher scores corresponding to worse QOL. Individual scores for each item are  
21 summed to create a total score ranging from 0 to 68.<sup>2</sup>  
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30 Univariable linear regression models were used to measure the bivariate relationship between  
31 each demographic and clinical variable and HiSQOL total score. Multivariable linear regression was used  
32 to assess the relationship between each variable and the HiSQOL total score while adjusting for all other  
33 covariates. Group differences and associations with QOL were expected to lessen when adjusting for flare  
34 frequency, since flare itself is a measure of disease activity and as such it is part of the process by which  
35 QOL is impaired. Accordingly, adjusting for flare frequency would reduce estimated differences in QOL  
36 between groups that differ in flare frequency. Multiple imputation by chained equations with 30  
37 imputations was used to account for missing data.  
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47 Among 1,927 participants completing the survey in clinic, 1,828 reported being diagnosed with  
48 HS by dermatologists, general practitioners, or other physicians and were eligible for analysis.  
49 Demographic and clinical characteristics of participants have been described previously.<sup>1,3</sup> Briefly, most  
50 patients were aged 18-40 years (62%), female (85%), either overweight or obese (79%), and nearly half  
51 were active smokers (44%).  
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3 Mean HiSQOL total score was 29.3 (SD 16.7), which corresponds to a moderate to very large  
4 effect in terms of established DLQI score bands.<sup>2</sup> Median total score was 28.5 (IQR 16-42). In bivariable  
5 analysis, factors associated with worse HS-related QOL included younger age, BMI >40.0, active  
6 smoking status, increasing flare frequency, depression and anxiety, higher number of comorbidities, high  
7 school education level or less, inability to work, and difficult or very difficult access to a dermatologist.  
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13 **(Table I)**

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15 In the multivariable adjusted linear regression model, differences in HiSQOL according to  
16 demographic and other factors were attenuated. **(Table I)** For example, adjusted mean HiSQOL  
17 difference between patients with BMI > 40 and BMI < 25.0 was reduced from 7.9 (95% CI 5.0, 10.8) to  
18 1.5 (95% CI -1.2, 4.1). Factors which remained strongly associated with HS-related QOL included  
19 disability ( $\beta=4.8$  vs. employed, 95% CI 2.7, 7.0), increasing number of comorbidities ( $\beta=1.5$ , 95% CI 0.8,  
20 2.2 per comorbidity) and very difficult access to a dermatologist ( $\beta=7.4$  vs. very easy, 95% CI 4.4, 10.4).  
21 Increasing flare frequency was strongly associated with lower HS-related QOL and showed a graded  
22 relationship. In subgroup analysis of American and Canadian patients, Black race was associated with  
23 similar HS-related QOL [ $\beta=0.5$ , 95% CI -3.7, 4.8] before adjustment for covariates, and worse HS-related  
24 QOL  $\beta=5.9$ , 95% CI 2.0-9.7] after covariate adjustment, compared to white race. **(Table I)**  
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37 Limitations include enrolment of participants from HS referral clinics, which may overrepresent  
38 experiences of patients with more severe disease. Response denominator could not be calculated.  
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60 In this Global VOICE analysis, patients with HS experienced high life impact related to their  
disease. Younger age, high BMI, active smoking, flares, depression, high comorbidity burden, disability,  
and difficult access to a dermatologist were associated with disease-related life impact in HS in  
unadjusted analysis. Age and access to a dermatologist had a graded relationship with life impact in  
unadjusted analysis. Attenuation of regression coefficients after adjusting for flare frequency suggests that  
increased flare frequency partially explains poorer disease-related QOL in certain groups. Black patients

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3 with HS may experience worse disease-specific life impact compared to whites, and this topic warrants  
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5 further study. In the absence of highly satisfactory treatments,<sup>3</sup> attention to factors, particularly modifiable  
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7 ones, that correlate with poor QOL in HS patients may reduce overall impact of disease.  
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10  
11 **Acknowledgements:** None  
12  
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14  
15  
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**References:**

1. Garg A, Neuren E, Cha D, Kirby JS, Ingram JR, Jemec GBE, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: results from the Global Survey of Impact and Healthcare Needs (VOICE) project. *J Am Acad Dermatol.* 2020;82(2):366-376.
2. Kirby JS, Thorlacius L, Villumsen B, Ingram JR, Garg A, Christensen KB, et al. The Hidradenitis Suppurativa Quality of Life (HiSQOL) score: development and validation of a measure for clinical trials. *Br J Dermatol.* 2020;183(2):340-348.
3. Midgett B, Strunk A, Akilov O, et al. Factors associated with treatment satisfaction in patients with hidradenitis suppurativa: results from the Global VOICE project [published online ahead of print, 2022 Jul 30]. *Br J Dermatol.* 2022;10.1111/bjd.21798. doi:10.1111/bjd.21798

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**Table 1. Mean difference in HiSQOL score according to patient characteristics**

Variable	Unadjusted mean HiSQOL difference <sup>a</sup> (95% CI)	p-value	Adjusted mean HiSQOL difference <sup>a,b</sup> (95% CI)	p-value
<b>Delay in diagnosis</b> (per 1-yr.)	-0.02 (-0.11, 0.08)	.67	-0.04 (-0.14, 0.05)	.36
<b>Comorbidity count</b> (per 1-unit increase)	2.4 (1.6, 3.1)	<.001	1.5 (0.8, 2.2)	<.001
<b>Age (yrs.)</b>				
18-30	Ref.	Ref.	Ref.	Ref.
31-40	-0.2 (-2.4, 2.0)	.87	-0.3 (-2.2, 1.7)	.80
41-50	-1.8 (-4.1, 0.4)	.11	-0.9 (-3.1, 1.3)	.42
51-60	-6.2 (-9.0, -3.3)	<.001	-4.2 (-7.1, -1.4)	.004
61 +	-7.6 (-13.3, -1.9)	.009	-3.9 (-9.0, 1.2)	.13
<b>Sex</b> , male vs. female (ref.)	-3.7 (-6.0, -1.3)	.003	-1.0 (-3.2, 1.1)	.34
<b>BMI category</b>				
Underweight/Normal weight (BMI < 25)	Ref.	Ref.	Ref.	Ref.
Overweight (BMI 25.0-29.99)	3.0 (0.4, 5.7)	.03	1.6 (-0.7, 4.0)	.17
Obese 1 (BMI 30.0-34.99)	2.2 (-0.6, 5.0)	.12	-0.2 (-2.6, 2.2)	.87
Obese 2 (BMI 35.0-39.99)	3.6 (0.6, 6.6)	.02	0.2 (-2.4, 2.9)	.85
Obese 3 (BMI ≥ 40)	7.9 (5.0, 10.8)	<.001	1.5 (-1.2, 4.1)	.28
<b>Smoking status</b> (Ref. = Never)				
Former smoker	2.1 (-0.1, 4.3)	.06	1.1 (-0.9, 3.0)	.30
Active smoker	4.9 (2.8, 6.9)	<.001	1.7 (-0.2, 3.6)	.08
<b>Education</b>				
College/university degree	Ref.	Ref.	Ref.	Ref.
Graduate school degree	-1.2 (-3.7, 1.3)	.34	-0.7 (-2.9, 1.5)	.55
High school	5.8 (3.9, 7.7)	<.001	2.1 (0.4, 3.8)	.02
Less than high school	4.4 (0.7, 8.1)	.02	3.5 (0.1, 6.8)	.04
<b>Married/in relationship</b> , Ref = No	-0.7 (-2.6, 1.1)	.42	-0.5 (-2.1, 1.1)	.52
<b>Employment</b> (Ref. = Employed)				
Not looking for work or Retired	1.6 (-0.9, 4.1)	.21	0.9 (-1.4, 3.1)	.45
Unemployed	2.8 (-0.1, 5.6)	.06	0.5 (-2.0, 3.1)	.67
Disabled	9.5 (7.2, 11.8)	<.001	4.8 (2.7, 7.0)	<.001
<b>Main physician for HS is a dermatologist</b> , Yes vs. No (ref.)	-2.0 (-3.7, -0.3)	.02	0.4 (-1.2, 2.0)	.62
<b>Access to a dermatologist</b>				
Very easy	Ref.	Ref.	Ref.	Ref.
Easy	0.8 (-1.9, 3.5)	.57	0.7 (-1.7, 3.2)	.56
Neutral	2.2 (-0.5, 5.0)	.11	2.1 (-0.4, 4.6)	.10
Difficult	5.4 (2.7, 8.2)	<.001	4.7 (2.2, 7.2)	<.001
Very difficult	11.8 (8.6, 15.0)	<.001	7.4 (4.4, 10.4)	<.001
<b>Depression diagnosis</b> , Ref = No	7.8 (6.1, 9.5)	<.001	3.1 (1.2, 4.9)	<.001
<b>Anxiety diagnosis</b> , Ref = No	6.6 (4.8, 8.3)	<.001	1.5 (-0.3, 3.4)	.10
<b>Flare frequency</b>				
Every 6 months	Ref.	Ref.	Ref.	Ref.
Every 3 months	4.5 (0.7, 8.4)	.02	3.6 (-0.2, 7.3)	.06
Monthly	11.7 (8.5, 14.9)	<.001	10.2 (7.1, 13.3)	<.001
Weekly	18.8 (15.5, 22.1)	<.001	15.5 (12.3, 18.7)	<.001
Daily	24.6 (21.3, 27.9)	<.001	20.6 (17.3, 23.9)	<.001

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3 a – Mean difference in HiSQOL total score compared to the reference group. Higher HiSQOL scores  
4 correspond to worse QOL impairment. Accordingly, negative mean differences imply better QOL  
5 compared to the reference group, and positive mean differences imply worse QOL compared to the  
6 reference group.  
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9 b – Derived from a multiple linear regression model including all variables in the table as predictors. No  
10 variable selection procedure was performed.  
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