

The Invisible Burden of a Visible Disease: Exploring Psychosocial Burden and Quality of Life Impairment in Vitiligo

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BACKGROUND

- Vitiligo is a chronic autoimmune disease characterized by patches of depigmentation on the skin or hair, or both.¹ The estimated prevalence of vitiligo ranges from 0.4 to 2% globally.²⁻⁵
- Vitiligo can be associated with emotional distress; social impacts; and impairment in work productivity, daily activities, and overall health related quality of life (HRQOL). However, vitiligo impacts vary substantially. Factors such as lesion noticeability, internalization of social stigma, cultural context, and learned coping mechanisms may amplify or dampen downstream outcomes⁶
- As vitiligo presents differently across affected individuals, it's important to identify the factors that shape downstream impacts. Doing so helps clarify treatment priorities and supports fair access to care by informing data-driven policies and appropriate evaluations of treatment benefit

OBJECTIVE

- To examine how psychosocial burden varies across clinical symptoms, disease history, and social context in adults with vitiligo in the United States (US) and Europe

METHODS

Study Design

- An online cross-sectional survey was administered to adults with vitiligo in the US and Europe (United Kingdom, Germany, France, Italy, and Spain) from March 2025 to July 2025
- Adults ≥ 18 years of age who previously completed a National Health and Wellness Survey (NHWS) in one of the study countries and self-reported ever having been diagnosed with vitiligo by a healthcare provider were eligible to complete the survey
 - The NHWS is an annual, cross-sectional, internet-based survey of adults (aged ≥18 years) conducted across several countries that collects patient reported information on health status, comorbidities, quality of life, healthcare use, etc
- The survey captured respondent demographics, clinical characteristics, treatment background, psychosocial burden, and internalized stigma
 - Patient-reported vitiligo disease burden was assessed using the Vitiligo Impact Patient Scale (VIPS) (Table 1)⁷
 - Internalized stigma was measured using the Patient Unique Stigmatization Holistic Tool in Dermatology (PUSH-D) instrument (Table 1)⁸

Statistical analysis

- Respondent characteristics were summarized descriptively
- Vitiligo disease burden (VIPS) scores were stratified by the following factors (Table 1):
 - Patient Global Impression of Severity – Facial Vitiligo (PGIS-F) – none to mild vs. moderate to very severe
 - Patient Global Impression of Severity – Total Body Vitiligo (PGIS-V) – none to mild vs. moderate to very severe
 - Years since diagnosis - ≤5 years vs. >5 years
 - Internalized stigma as measured by PUSH-D score – mild vs. moderate to severe
 - Body surface area (BSA) - 0-<4% vs. ≥ 4%. BSA was measured using the Self-Assessment Vitiligo Extent Score (SA-VES)
 - Face involvement - Yes vs. No
- Associations between vitiligo disease burden and respondent subgroups were tested using Chi-squared tests, ANOVA/2-Sample t-tests as appropriate
- Significant associations were reflected as p < 0.05

Table 1. Overview of VIPS, PUSH-D, PGIS-F, PGIS-V

Instrument Name	Description	Number of items	Domains	Score
Vitiligo Impact Patient Scale (VIPS)	Measures patient reported vitiligo disease burden using Likert-style frequency response options to capture how often stigma related feelings, thoughts, or behaviors occur.	29	psychosocial functioning, social functioning, relationship functioning, and treatment burden	0-95 (higher scores = greater burden)
Patient Unique Stigmatization Holistic Tool in Dermatology (PUSH-D)	Measures internalized stigma related to dermatologic conditions using Likert-style frequency response options to capture how often burden related experiences occur.	17	Felt stigma, enacted stigma	Mild stigma: < 14 Moderate to severe stigma: ≥14
Patient Global Impression of Severity – Face (PGIS-F)	Measures patient reported severity of vitiligo on the face using Likert-style severity response option to capture how severe facial involvement is perceived to be.	1	Severity of facial vitiligo	0=none, 1= mild, 2= moderate, 3 = severe, 4 = very severe
Patient Global Impression of Severity – Overall Vitiligo (PGIS-V)	Measures patient reported severity of vitiligo on the body using Likert-style severity response option to capture how severe the condition is perceived to be.	1	Severity of body vitiligo	0=none, 1= mild, 2= moderate, 3 = severe, 4 = very severe

RESULTS

- 155 respondents were included in the total sample (Table 1)
- The mean age was 58 years and 51% were female (Table 1)
- 56.1% of respondents reported having a university degree or higher

Table 2. Sociodemographic Characteristics

	Total Sample N=155	
	N	%
Age (years)		
Mean (SD)	58.13 (15.86)	
18-25	4	2.6%
26-35	14	9.0%
36-45	19	12.3%
46-55	23	14.8%
56-65	28	18.1%
66-75	48	31.0%
76+	19	12.3%
Sex		
Male	76	49.0%
Female	79	51.0%
Race/ethnicity (US only)		
Non-Hispanic white	68	77.3%
Non-Hispanic Black/African American	6	6.8%
Hispanic	11	12.5%
Other	3	3.4%
Marital status		
Married/living with partner	99	63.9%
Single, never married/divorced/separated/widowed	56	36.1%
University education		
Less than university degree	68	43.9%
University degree or higher	87	56.1%
Annual household income		
Below country median	53	34.2%
Above country median	97	62.6%
Decline to answer	5	3.2%
Health insurance type (US only)		
No insurance	2	2.3%
Private	43	48.9%
Public	43	48.9%

LIMITATIONS

- Cross-sectional design may introduce recall bias, as responses reflect participants perceived "current" state at a single point in time
- Sample was heavily skewed towards an older population limiting generalizability
- Age-related differences may reflect underlying factors such as longer disease duration or coping adaption rather than age alone
- The selected stratification variables (facial severity, body severity, years since diagnosis) are likely correlated, introducing confounding bias
- Analysis focused on bivariate analyses which resulted in strong associations between clinical characteristics, stigma, and QOL impacts. Multivariable analyses would provide further insight into the potential confounding

- The mean time since first vitiligo diagnosis was 20.84 years (Table 3)
- Facial vitiligo severity was reported as none (31%), mild (31.6%), moderate (27.1%), severe (7.1%) and very severe (3.2%) (Table 3)
- Total body vitiligo severity was reported as none (3.9%), mild (37.4%), moderate (41.3%), severe (14.2%), and very severe (3.2%) (Table 3)
- Most respondents were Fitzpatrick skin type I-III (64.5%), followed by IV-VI (32.3%) (Table 3)
- Body areas most commonly affected include the upper extremities (76.1%), face (58.1%), trunk/torso (62.6%), and lower extremities (61.3%) (Table 3)
- The mean Self Assessment Vitiligo Extent Score (SA-VES) was 7.10 (Table 3)

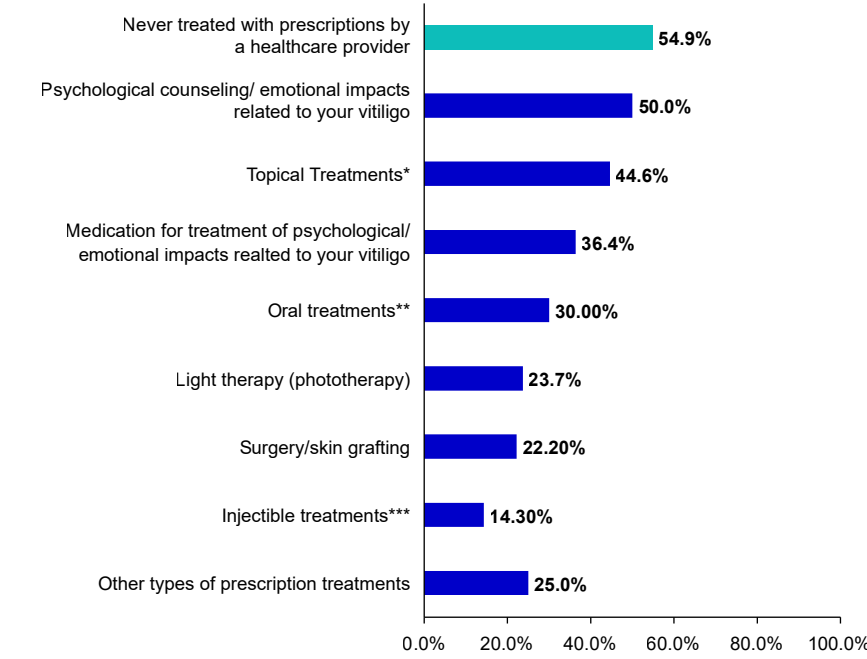
Table 3. Vitiligo Disease History Among Adults with Vitiligo

	Total Sample N=155	
	N	%
Years since first vitiligo diagnosis		
Mean (SD)	20.84 (17.63)	
Median	15.00	
(Q1, Q3)	(5.00, 30.00)	
Min, Max	0.00, 75.00	
Severity of vitiligo on face as of today		
None	48	31.0%
Mild	49	31.6%
Moderate	42	27.1%
Severe	11	7.1%
Very severe	5	3.2%
Decline to answer	0	0.0%
Severity of vitiligo on total body as of today		
None	6	3.9%
Mild	58	37.4%
Moderate	64	41.3%
Severe	22	14.2%
Very severe	5	3.2%
Decline to answer	0	0.0%
Fitzpatrick Type (Derived from skin tone)		
I-II	100	64.5%
III-IV	50	32.3%
V-VI	4	2.6%
Prefer not to answer	1	0.6%
Part(s) of body affected by vitiligo (currently) overall		
Head and neck	109	70.3%
Face (all regions)	90	58.1%
Face, excluding mouth and nostrils	72	46.5%
Upper extremities	118	76.1%
Trunk/Torso	97	62.6%
Lower extremities	95	61.3%
Any area in the body excluding face (Excludes Face-eye area, Face-mouth and nostrils, and Face-other parts of my face)	147	94.8%
SA-VES	Valid N = 122	
Self-Assessment Vitiligo Extent Score (SA-VES) [% Total BSA]		
Mean (SD)	7.10 (12.90)	
Median	1.86	
(Q1, Q3)	(0.50, 7.00)	
Min, Max	0.00, 66.38	
SA-VES: %Total BSA categorical		
0-<4	79	64.8%
4-10	22	18.0%
>10	21	17.2%

¹One of the affected questions from the initial soft launch of data collection. Affected respondents (N=33) excluded from analyses.

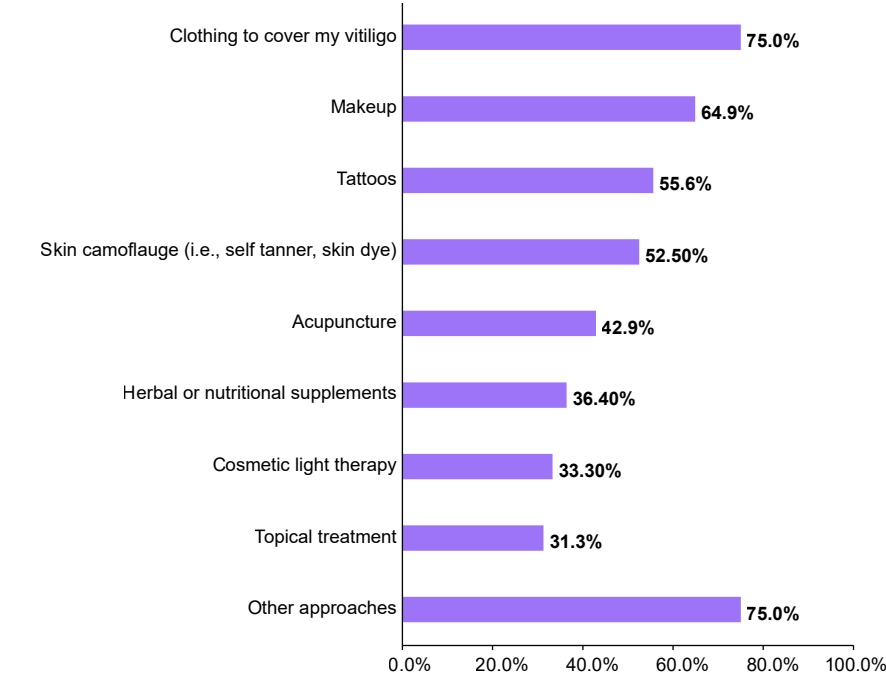
- 43.3% of respondents reported they were currently using a prescription treatment (non-mental-health related) to address their vitiligo
- Topical prescription treatments were the most frequently used therapy, reported by 44.6% respondents currently using prescription treatments (Figure 1)
- 54.9% of respondents report never receiving prescription treatments for vitiligo which may highlight unmet treatment engagement or access (Figure 1)
- Respondents frequently reported using non-prescription treatment/coping resources to address vitiligo symptoms or impact. The most common included clothing to cover their vitiligo (75.0%), makeup (64.9%), and tattoos (55.6%)

Figure 1. Current Therapies Prescribed by a Healthcare Provider for Vitiligo Symptoms/Impacts



* Treatments applied to the skin, e.g., creams, lotions, foams, gels, ointments, sprays
** Treatments taken by mouth, e.g., pills, tablets, capsules
*** Injection in the muscle, under the skin, in a vein

Figure 2. Current Non-Prescription Coping Resources Used to Address Vitiligo Symptoms/Impacts



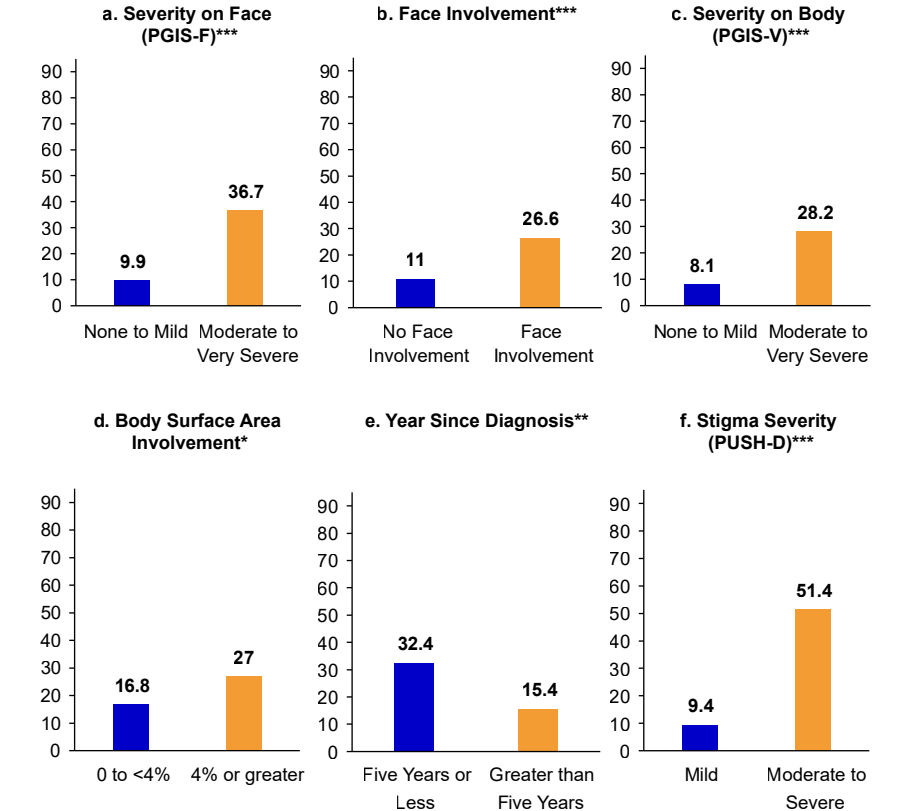
- 122 adults had available VIPS (Table 5)
- The mean (SD) VIPS score was 20.4. (24.1) (Figure 3)
- Adults with moderate-to-very severe facial vitiligo (36.7 [27.26]) had higher VIPS scores compared to those with none-to-mild facial vitiligo (9.9 [14.01]; p < 0.001) (Figure 3)

DISCLOSURES

The study was sponsored by Pfizer.
SKK, HS, BA, GG, and TA are employees and stockholders of Pfizer Inc. MM, SH, NO, NP, AD, KKC, and EM are employees of Oracle Life Sciences, which received funding from Pfizer to conduct the study. PC is supported by the University of Illinois Chicago/Pfizer Inc. Health Economics and Outcomes Research Fellowship. VE has received honoraria and/or academic support from AbbVie, Almirall, Genesis Pharma, Incyte Corporation, La Roche-Posay, L'Oréal and Pfizer; is a scientific advisor for the UK Vitiligo Society; and is a Section Editor for the *BJD*. JE is a consultant for AbbVie, Incyte, La Roche-Posay, Pfizer, Pierre Fabre, Sanofi, and Vela Bio.

- Adults with moderate to very severe vitiligo on the body had higher VIPS scores (28.2 [25.6]) than those with none to mild severity on the body (8.1 [14.6]; p < 0.001) (Figure 3)
- Shorter disease duration was significantly associated with higher VIPS scores since vitiligo diagnosis had higher VIPS scores (≤ 5 years; 32.4 [29.1]) compared to those with a longer disease duration (>5 years; 15.4 [19.8]; p = 0.002) (Figure 3)
- Respondents frequently reported moderate to severe stigma (PUSH-D score ≥14) also reported significantly higher VIPS scores (51.4 [22.4]) than those with mild internalized stigma (PUSH-D score <14; 9.4 [12.0]; p < 0.001) (Figure 3)

Figure 3. VIPS Score by Clinical Characteristics, Disease Severity, and Perceived Stigma



* p < 0.05; ** p < 0.01; *** p < 0.001

CONCLUSIONS

- Vitiligo-related psychosocial burden, as measured by the VIPS, was significantly greater in adults with more severe disease on the face and body, more recent diagnosis, and greater perceived vitiligo stigma
- Stigma was strongly linked to visible disease and limited time to adapt
- Visibility and self-perceived severity may contribute to worsened psychosocial outcomes
- Early disease represents a period of heightened vulnerability for psychosocial and QOL impacts
- Early intervention strategies such as treatments addressing visible/extensive disease and psychological support may help mitigate QOL Impacts

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