

The Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in the United States: Findings From the Global VALIANT Study

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Introduction

- Vitiligo is a chronic autoimmune disease characterized by the destruction of melanocytes, resulting in pale or white patches of skin¹
- Studies have shown that vitiligo greatly affects quality of life (QoL) and may cause psychological impairment similar to that of other skin diseases, such as psoriasis or eczema^{2,3}
- Anxiety and depression have been reported in up to 67.9% and 62.3% of patients with vitiligo, respectively²
 - Patients with vitiligo were approximately 5 times more likely to suffer from depression than healthy individuals^{4,5}
- The population-based Vitiligo and Life Impact Among International Communities (VALIANT) study sought to understand the burden of vitiligo on patients' QoL from their perspective in 17 countries

Objectives

- To understand the impact of vitiligo on the QoL and mental health of adult patients in the United States

Methods

Study Design and Patients

- This cross-sectional online survey recruited adult patients (aged ≥18 years) diagnosed with vitiligo by a healthcare professional

- Patients were recruited using a general population sampling approach from a network of consumers in Australia, Brazil, Canada, China, Egypt, France, Germany, India, Italy, Japan, Philippines, Saudi Arabia, South Africa, Spain, Thailand, United Kingdom, and United States
 - Here we present findings from the United States
- Patients completed a self-administered online screener designed to capture high-level demographics, confirm diagnosed vitiligo, and provide consent before continuing to the 25-minute survey
- Patient responses regarding their emotional well-being were sought to understand the effect of vitiligo on various attitudinal metrics, including daily life and activities, impact on self-esteem, depression, anxiety, and stigmatization
 - QoL was assessed using the Vitiligo Impact Patient scale (VIPs), a validated tool encompassing a number of areas in which a patient's life may be impacted because of their vitiligo⁶
 - Symptoms consistent with depression were screened via the validated nine-item Patient Health Questionnaire (PHQ-9) depression screener⁷
- The extent of vitiligo was assessed using the validated Self Assessment Vitiligo Extent Score (SA-VES) tool,⁸ which uses an array of validated images for the patient to self-select, indicating how many vitiligo lesions are on each location of the body, and estimates the affected body surface area (BSA)

Statistical Analyses

- Data were analyzed using descriptive statistics, with mean (SD) and median (range) for continuous variables and percentages for discrete variables
- Statistical comparisons were made between subgroups (eg, fair vs dark skin), with significance conferred at the level of $P<0.05$; no corrections were made for multiple testing

Results

Patient Characteristics

- Of 95,623 participants invited to participate in the survey in the United States, 637 (0.7%) completed the survey, and 608 (0.6%) were included in the analysis
- Among the 608 included patients, 57.9% were male and 91.4% were white (**Table 1**)
 - Patients' median (range) age was 36 (18–83) years
 - Most patients reported Fitzpatrick skin phototypes I–III (71.1%)

Table 1. Patient Demographics and Clinical Characteristics

Characteristic	All Patients (N=608)
Age, median (range), y	36 (18–83)
Male, n (%)	352 (57.9)
White, n (%)	556 (91.4)
Hispanic, n (%)	51 (8.4)
Fitzpatrick skin phototype,* n (%)	
I	91 (15.0)
II	240 (39.5)
III	101 (16.6)
IV	103 (16.9)
V	64 (10.5)
VI	9 (1.5)
Disease duration, mean (SD), y	11.0 (13.4)
Time before diagnosis, mean (SD), y	1.6 (4.7)
Affected BSA, [†] median (range), %	4.46 (0.02–73.88)
Affected BSA range, n (%)	
<1% [‡]	165 (27.1)
1%–5%	158 (26.0)
>5%	285 (46.9)

BSA, body surface area; SA-VES, Self Assessment Vitiligo Extent Score.

* Fitzpatrick skin phototypes are defined as follows: type I, pale white skin; type II, white skin; type III, light brown skin; type IV, moderate brown skin; type V, dark brown skin; type VI, deeply pigmented dark brown to black skin.

[†] BSA was estimated using the SA-VES tool.

[‡] 6 patients reported a BSA of zero.

Disease-Related QoL Concerns

- More than half of patients (53.5%) reported that managing their vitiligo on a daily basis was burdensome, and 55.8% reported telling themselves that “life would be very different without vitiligo,” per the VIPs (**Table 2**)
 - The VIPs impact rating indicated significantly more burden among patients with darker skin compared with those with fairer skin types (Fitzpatrick phototypes IV–VI vs I–III: mean, 32.5/60 vs 28.2/60; $P<0.05$)
 - Significantly higher VIPs impact ratings were reported among patients with darker vs fairer skin regarding dipping into savings for vitiligo treatment (67.0% vs 48.4%; $P<0.05$) and experiencing vitiligo as a daily handicap (58.5% vs 48.8%; $P<0.05$)

Table 2. Patient QoL Concerns per the VIPs*

Characteristic, n (%)	Overall (N=608)	Fitzpatrick Skin Phototype	
		I–III (n=432)	IV–VI (n=176)
I feel discouraged because of my vitiligo	49.7	43.5	64.8
My vitiligo has repercussions on my physical appearance	53.1	50.5	59.7
The progression of my vitiligo worries me (makes me anxious)	58.9	55.3	67.6
My reflection in the mirror makes me anxious	51.2	46.5	62.5
I dread nice weather because of my vitiligo	55.8	53.7	60.8
Questions about my vitiligo bother me, disturb me	51.0	47.5	59.7
I tend to withdraw into myself because of my vitiligo	52.0	47.0	64.2
I dread first meetings because of my vitiligo	53.1	50.9	58.5
I dip into my savings to treat my vitiligo	53.8	48.4	67.0
I make sacrifices to afford my vitiligo treatments	51.8	50.5	55.1
Managing my vitiligo on a daily basis is a burden	53.5	52.3	56.3
I often tell myself that my life would be very different without vitiligo	55.8	53.5	61.4
I experience my vitiligo as a daily handicap	51.6	48.8	58.5
My vitiligo has a negative impact on my libido (sexual desire)	50.8	47.2	59.7
My vitiligo is an obstacle (a barrier) to my sexuality	49.8	44.7	62.5
In the evening, once I've applied all the creams, I feel depressed	50.2	45.4	61.9
I have had to change my vacations, leisure activities because of my vitiligo	48.7	47.2	52.3
I am ashamed of the consequences of my vitiligo	45.4	41.4	55.1
I feel that medicine has abandoned me	46.9	42.6	57.4
The looks I get from children because of my vitiligo are hurtful	50.7	48.8	55.1

Less burden

40%–44%

45%–49%

50%–54%

55%–59%

60%–64%

65%–69%

More burden

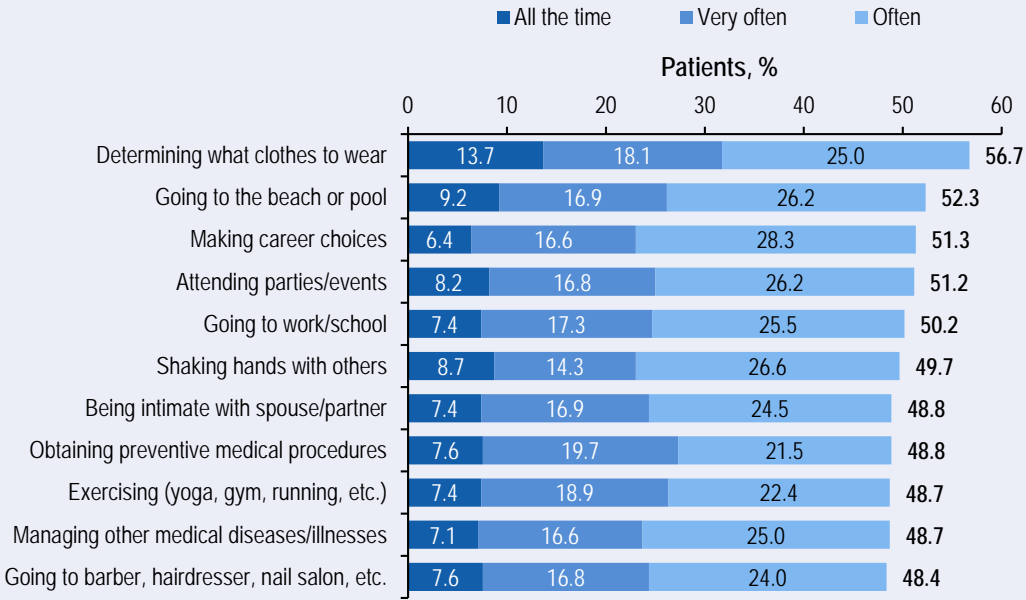
QoL, quality of life; VIPs, Vitiligo Impact Patient scale.

* A summary of responses including *often*, *very often*, and *all the time* are shown. Twenty questions from the VIPs impact rating were completed as validated with some attributes applying only to fairer or darker skin types.

Daily Impact of Vitiligo

- Patients most commonly reported that vitiligo frequently affected their clothing choices (56.7%), going to social activities (beach/pool, 52.3%; parties/events, 51.2%), and making career choices (51.3%; **Figure 1**)
 - Across activities, more patients with darker skin types (vs fairer skin types) and >5% affected BSA (vs 1%–5% and <1% affected BSA) reported that vitiligo often impacted their daily activities

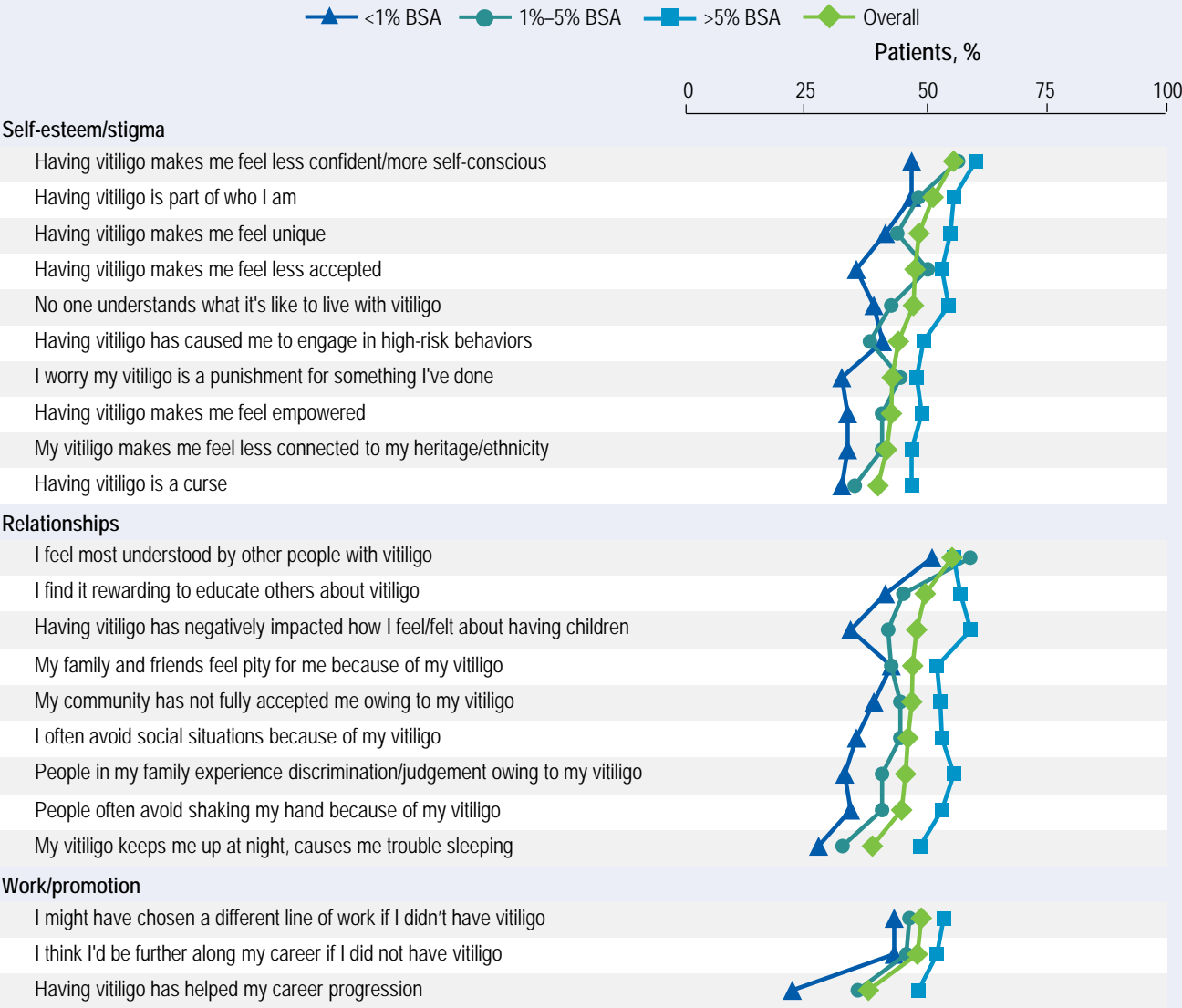
Figure 1. Daily Impact of Vitiligo on Patients



Impact of Vitiligo on Psychosocial QoL

- Many patients reported having missed personal obligations, including work, for vitiligo treatments (60.0%) or because of disease-related anxiety (47.0%)
- Overall, 55.4% of patients reported that having vitiligo makes them feel less confident or more self-conscious, 55.1% reported feeling most understood by other people with vitiligo, and 48.7% might have chosen different careers if they did not have vitiligo (**Figure 2**)
 - More patients with >5% affected BSA vs 1%–5% or <1% affected BSA reported being impacted across all self-esteem, relationship, and work categories

Figure 2. Perceived Impact of Vitiligo on Self-Esteem, Relationships, and Careers**

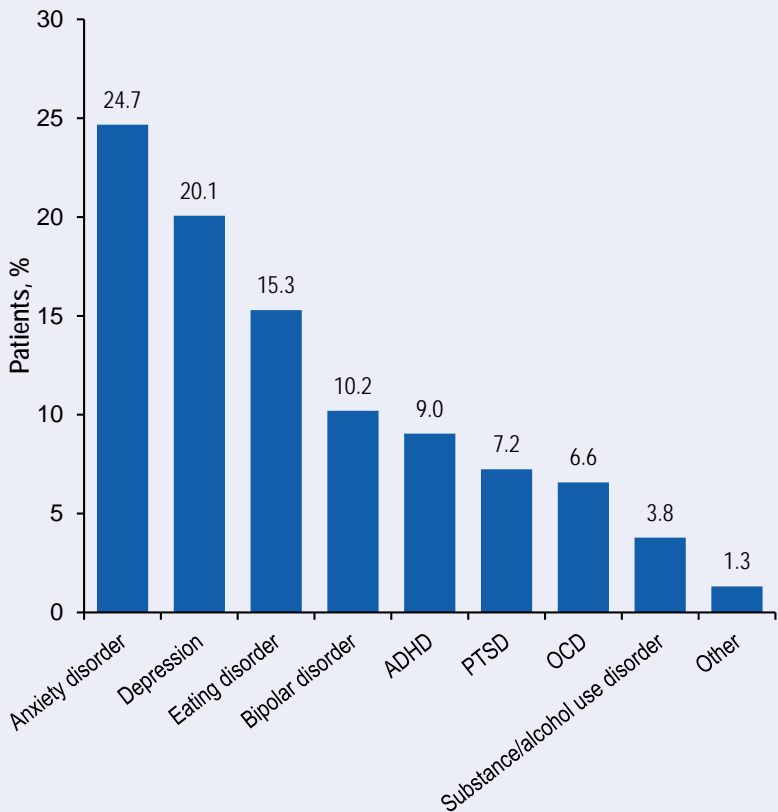


BSA, body surface area; SA-VES, Self Assessment Vitiligo Extent Score.
* Includes patients who responded *strongly agree* or *agree*.
† BSA was determined using the SA-VES.

Impact of Vitiligo on Mental Health

- About half of patients (52.3%) reported having been diagnosed with a mental health condition by a medical professional; anxiety (24.7%) and depression (20.1%) were the most common diagnoses (Figure 3)

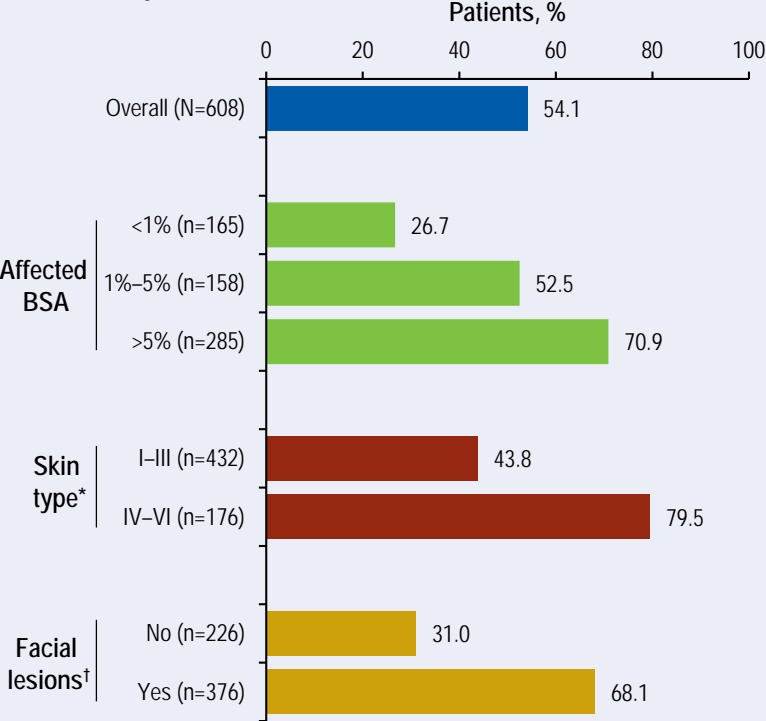
Figure 3. Formally Diagnosed Mental Health Conditions Among Patients With Vitiligo



ADHD, attention deficit hyperactivity disorder; OCD, obsessive-compulsive disorder; PTSD, posttraumatic stress disorder.

- Although 20.1% of patients were formally diagnosed with depression, the PHQ-9 depression screener indicated that 77.6% of patients had symptoms consistent with depression
 - More than half of patients (54.1%) exhibited moderate to severe symptoms of depression (Figure 4)

Figure 4. Moderate to Severe Depressive Symptoms As Assessed by the PHQ-9

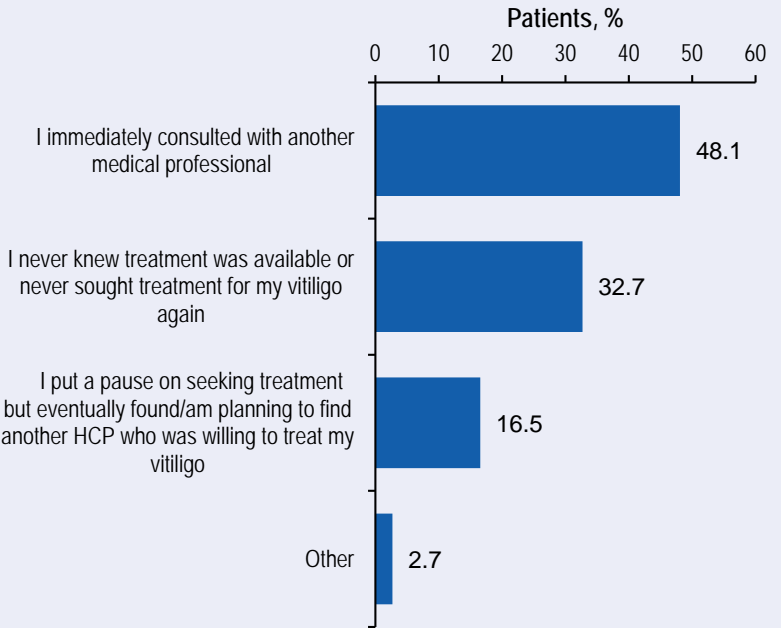


PHQ-9, nine-item Patient Health Questionnaire.
* Fitzpatrick skin phototypes I-III were characterized as fairer and phototypes IV-VI as darker skin types.
† Patients with 0% affected BSA (n=6) were excluded from analysis of facial lesions.

Vitiligo Management

- The majority of patients (60.5%) were told by a physician that their vitiligo could not be cured or treated
 - As a result, 32.7% of 260 healthcare-seeking patients stopped pursuing treatment (Figure 5)
- Although the majority of patients are hopeful that new treatments will help them someday (69.6%), many expressed little desire to treat their vitiligo (43.4%) or had given up trying to find an effective treatment (41.0%)

Figure 5. Patient Responses to Being Advised by an HCP That Their Vitiligo Could Not Be Treated (n=260)



HCP, healthcare professional.

Limitations

- The current study is limited by selection bias associated with its online nature (ie, only available to patients with internet access) although efforts were made to conduct in-person interviews in populations with limited internet access if needed to reach desired sample size
- Potential errors in measurement inherent to patient-reported outcomes studies may have occurred

Conclusions

- **The results of this survey indicate that vitiligo impacts patients' daily lives, emotional well-being, and careers**
- **These findings highlight an unmet need in understanding the QoL burden among patients living with vitiligo**
- **Patients alter their behaviors, express clear discontent, and have symptoms consistent with depression, which may be undiagnosed**
 - **Although 20.1% of patients were diagnosed with depression, 54.1% had symptoms consistent with moderate to severe depression**
- **Some patients may be discouraged from seeking treatment, with 60.5% reporting being told that their vitiligo could not be treated**

Disclosures

KB, AL and TDJ are employees and shareholders of Incyte Corporation. JG has served as a consultant for AbbVie, Avita Medical, Concert Pharmaceuticals, Incyte Corporation, Mitsubishi Tanabe Pharma Corporation, and Pfizer. CL is a co-owner of Envision Health Partners, who received funding for conducting this project from Incyte Corporation. JEH has served as a consultant for AbbVie, Aclaris Therapeutics, BiologicsMD, EMD Serono, Genzyme/Sanofi, Janssen, Pfizer, Rheos Medicines, Sun Pharmaceuticals, TeVido BioDevices, The Expert Institute, 3rd Rock Ventures, and Villarís Therapeutics; has served as an investigator for Aclaris Therapeutics, Celgene, Dermira, EMD Serono, Genzyme/Sanofi, Incyte Corporation, LEO Pharma, Pfizer, Rheos Medicines, Stiefel/GlaxoSmithKline, Sun Pharmaceuticals, TeVido BioDevices, and Villarís Therapeutics; holds equity in Aldena Therapeutics, NIRA Biosciences, Rheos Medicines, TeVido BioDevices, and Villarís Therapeutics; is a scientific founder of Aldena Therapeutics, NIRA Biosciences, and Villarís Therapeutics; and has patents pending for IL-15 blockade for treatment of vitiligo, JAK inhibition with light therapy for vitiligo, and CXCR3 antibody depletion for treatment of vitiligo. IHH has served as an advisory board member for AbbVie; a consultant for Boehringer Ingelheim, Galderma Laboratories LP, Incyte Corporation, Pfizer, and UCB; a principal investigator for Avita, Bayer, Estée Lauder, Ferndale Laboratories, Incyte Corporation, Lenicura, L'Oréal, Pfizer, and Unigen; a subinvestigator for Arcutis; president of the HS Foundation; and a board member of the Global Vitiligo Foundation. KE is a consultant for AbbVie, Incyte Corporation, La Roche-Posay, Pfizer, Pierre Fabre, Sanofi, and Viela Bio.

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