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ORIGINAL ARTICLE

Vitiligo patient population and disease burden in France: VIOLIN study results from the CONSTANCES cohort

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Abstract

Background: Vitiligo is a chronic autoimmune disease resulting in skin depigmentation.

Objectives: This study assessed the prevalence, disease burden and treatment of vitiligo in France.

Methods: VIOLIN was a cross-sectional study nested in the national CONSTANCES cohort, which consists of randomly selected adults aged 18–69 years in France. In VIOLIN, longitudinal data were collected prospectively from 158,898 participants during 2012–2018 and linked to the National Health Data System (SNDS), a healthcare utilization database. Patients with physician-diagnosed vitiligo were matched (1:3) with control participants based on age, sex, geographic region, year of inclusion and skin phototype. Patients completed a questionnaire in 2022 to collect disease characteristics, disease burden and quality-of-life (QoL) data.

Results: Vitiligo prevalence was 0.71% (681/95,597) in 2018. The mean age in the vitiligo population was 51.2 years; 51.4% were women. Most patients (63%) were diagnosed before age 30 years, mainly by dermatologists (83.5%). Most patients (81.1%) had visible lesions (i.e. on face, hands). Vitiligo was limited to <10% of the body surface area (BSA) in 85.8% of patients. Comorbidities including thyroid disease (18.0% vs. 9.0%), psoriasis (13.7% vs. 9.7%), atopic dermatitis (12.4% vs. 10.3%), depression (18.2% vs. 14.6%) and alopecia areata (4.3% vs. 2.4%) were significantly more common in patients with vitiligo versus matched controls ($n = 2043$). QoL was significantly impaired in patients with >5% BSA involvement or visible lesions, particularly with ≥10% facial involvement. Vitiligo-specific instruments (i.e. Vitiligo Impact Patient scale and Vitiligo-specific QoL instrument) were more sensitive to QoL differences among subgroups versus general skin instruments, and generic instruments were least sensitive. Most patients (83.8%) did not receive any prescribed treatment.

Conclusions: Patients with vitiligo in France have a high disease burden, particularly those with visible lesions or higher BSA involvement. Most patients are not receiving treatment, highlighting the need for new effective treatments and patient/physician education.

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INTRODUCTION

Vitiligo is a chronic autoimmune disease characterized by the loss of epidermal melanocytes, resulting in depigmented lesions.[1] The onset of vitiligo can occur at any age, but typically begins before 30 years of age.[2] The psychosocial consequences of vitiligo can be devastating, particularly among adolescents and patients with vitiligo lesions (i.e. depigmentation) in visible areas such as the face and hands.[3]

The prevalence of vitiligo diagnoses in Europe ranges from 0.2% to 0.8%, with country-specific and methodologic differences.[4,5] Until recently, there were no approved repigmentation treatments in Europe for patients with vitiligo. European treatment guidelines for vitiligo published in 2013 recommend the use of phototherapy and immunosuppressants, such as corticoids, dermocorticoids and topical calcineurin inhibitors.[6] In 2023, the European Medicines Agency approved ruxolitinib cream for the treatment of nonsegmental vitiligo with facial involvement in adults and adolescents aged ≥12 years.[7]

There is a lack of data regarding disease burden, quality of life (QoL) and treatment patterns among patients with vitiligo. Using the CONSTANCES cohort, the VIOLIN study aimed to describe the prevalence, disease burden and conventional treatment of vitiligo in real-world settings in France. The relationship between clinical characteristics of vitiligo (e.g. the extent of vitiligo and lesion location) and different patient-reported QoL assessments was also evaluated.

MATERIALS AND METHODS

Data sources for patient identification

The CONSTANCES cohort was designed as an epidemiologic research infrastructure consisting of randomly selected adults aged 18–69 years in the French population.[8] Data were collected prospectively from more than 210,000 participants from 2012 to 2020. Participants were invited to complete a questionnaire and undergo a comprehensive health examination at enrolment followed by a yearly self-administered questionnaire and health examination every 4 years. Collected data include demographic and social characteristics, socioeconomic status, behavioural and occupational factors, self-reported health scales, long-term chronic diseases and hospitalizations, and healthcare utilization and services received.

The *Système National des Données de Santé* (SNDS; National Health Data System) is a population-based database that includes inpatient and outpatient healthcare consumption for all patients covered by public health insurance.[9] Healthcare consumption data are available beginning in 2007 for participants in the CONSTANCES cohort. Data in the SNDS are linked with the CONSTANCES cohort based on a unique identifier; thus, data for each patient were available from both data sources.

Study design

In 2018, a questionnaire related to skin diseases was sent to participants in the CONSTANCES cohort. Patients reporting vitiligo on this 2018 questionnaire were sent a follow-up questionnaire in 2022. Patients with vitiligo who completed both questionnaires, reported physician confirmation of vitiligo in either questionnaire, and reported the persistence of vitiligo lesions in 2022 were included in this analysis. Participants who reported not having vitiligo in 2018 were matched with patients with vitiligo (3:1) using a propensity score based on age, sex, geographic region, year of inclusion in the CONSTANCES cohort and Fitzpatrick skin phototype. Patients with or without vitiligo for whom SNDS data were not available and patients with malignant melanoma identified in the 2020 follow-up questionnaire or recorded in the SNDS were excluded from the analysis to exclude melanoma-associated leukoderma.

Data related to patient demographics, comorbidities and general health were collected in the CONSTANCES cohort. Prescribed treatment data were collected in the SNDS database, although the indications for these treatments were not captured. The 2018 questionnaire assessed the severity of vitiligo on a 10-point scale (1 [not at all severe] to 10 [extremely severe]). The 2022 questionnaire collected vitiligo-specific data. Severity and location of vitiligo on the body (e.g. face, neck, hands and genitals) were assessed using the Self-Assessment Vitiligo Extent Score (SA-VES).[10] QoL patient-reported outcomes (PROs) included the EuroQoL 5-Dimensions 5-Levels questionnaire (EQ-5D-5L; range, 0–1 [lower scores indicate greater burden]),[11] Dermatology Life Quality Index (DLQI; range, 0–30 [higher scores indicate greater impairment]),[12] Patient Unique Stigmatization Holistic Tool in Dermatology (PUSH-D; range, 0–85 [higher scores indicate greater stigma]),[13] Vitiligo Impact Patient scale (VIPs; range, 0–95 [higher scores indicate greater burden]),[14] Vitiligo-specific Quality of Life (VitiQoL; range, 0–90 [higher scores indicate greater burden])[15] assessment and the Center for Epidemiologic Studies Depression Scale (CES-D; range, 0–60 [higher scores indicate more depression symptoms]).[16] The 2022 questionnaire also collected data regarding nonprescription treatment.

The study was conducted in accordance with the ethical principles of the Declaration of Helsinki and Good Clinical Practice. The CONSTANCES cohort was approved by the French national data protection authority (Authorization No. 910486) and the INSERM review board (Authorization No. 01-011). All participants gave their informed consent to participate.

Statistical analysis

Patient demographics and clinical characteristics are reported using descriptive statistics; no imputation was applied for missing data. For qualitative variables, the chi-square test was applied except for theoretical numbers <5, in which case Yates continuity correction or the Fisher exact test was used. For quantitative variables, a Student *t*-test or an analysis of variance was used

when the distribution was close to normal (i.e. Shapiro–Wilk test was not significant); nonparametric tests (e.g. Wilcoxon, Kruskal–Willis) were used for abnormal distributions. Statistical analysis was performed using SAS® v9.4 (SAS Institute).

Prespecified subgroup analyses were performed in patients with or without vitiligo on visible areas (i.e. face and/or hands) as well as by body surface area (BSA) per SA-VES (≤5% vs. >5%) and skin phototype (I–III vs. IV–VI). A subgroup analysis by facial involvement per SA-VES (<10% vs. ≥10%) was done post hoc.

RESULTS

Patients

The skin disease questionnaire was sent to 158,898 participants in 2018, and 99,209 participants responded. Among the 95,597 participants who completed the survey question regarding vitiligo, 86,078 reported that they had ($n = 1605$) or did not have ($n = 84,473$) vitiligo (Figure 1). Of the 1605 patients who reported vitiligo, 1156 (72%)

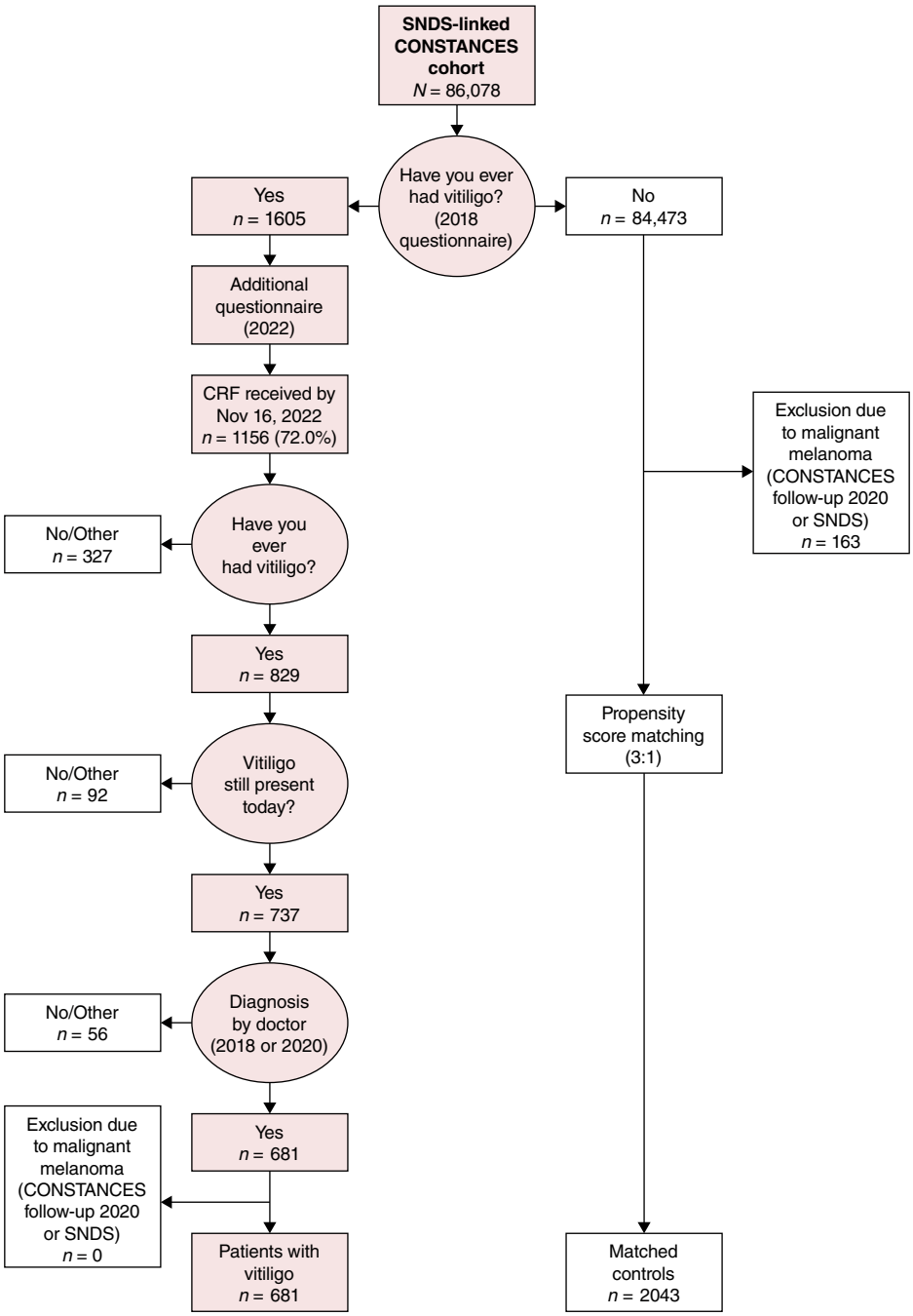

FIGURE 1 Study design flow chart. CRF, case report form; SNDS, Système National des Données de Santé (National Health Data System).

returned the 2022 questionnaire; 681 of those patients had physician-diagnosed vitiligo that was still present in 2022 and were included in this analysis. The control group included 2043 participants who did not report having vitiligo. Patient demographics, including age and sex, were similar between matched patients with and without vitiligo (Table 1). A significantly greater proportion of patients with vitiligo versus controls had autoimmune comorbidities, including thyroid disease (18.0% vs. 9.0%, respectively; $p < 0.0001$) and type 1 diabetes (0.8% vs. 0.1%; $p = 0.03$), as well as skin diseases such as atopic dermatitis (12.4% vs. 10.3%; $p = 0.0008$), psoriasis (13.7% vs. 9.7%; $p < 0.0001$) and alopecia areata (4.3% vs. 2.4%; $p = 0.004$; Table 2).

Vitiligo prevalence and disease characteristics

The crude prevalence of physician-diagnosed vitiligo was 0.71% (681/95,597); men and women were equally

TABLE 1 Characteristics of patients with vitiligo and matched controls.

Characteristic	Vitiligo ($n = 681$)	Control ($n = 2043$)	p Value
Age at inclusion, years			0.6583
Mean (SD)	51.2 (12.5)	51.4 (12.6)	
Median (Q1; Q3) [range]	52.5 (42.0; 62.0) [19.5–72.0]	53.5 (42.0; 62.5) [19.0–72.0]	
Age category, *n* (%)			0.6869
18 to <30 years	37 (5.4)	117 (5.7)	
30 to <40 years	101 (14.8)	312 (15.3)	
40 to <50 years	163 (23.9)	435 (21.3)	
50 to <60 years	170 (25.0)	513 (25.1)	
≥60 years	210 (30.8)	666 (32.6)	
Women, *n* (%)	350 (51.4)	1072 (52.5)	0.8892

Abbreviations: Q1, quartile 1; Q3, quartile 3.

TABLE 2 Comorbidities in patients with vitiligo and matched controls.

Comorbidity, *n* (%)	Vitiligo ($n = 681$)	Control ($n = 2043$)	p Value
At inclusion			
Depression with treatment	121 (18.2)	294 (14.6)	0.0290*
Thyroid disease	120 (18.0)	180 (9.0)	<0.0001****
Hypertension	83 (12.5)	266 (13.2)	0.6055
Treated hypercholesterolaemia	68 (10.4)	183 (9.1)	0.3596
Asthma	68 (10.2)	174 (8.7)	0.2342
Type 2 diabetes	14 (2.1)	42 (2.1)	0.9579
Suicide attempt(s)	12 (1.8)	25 (1.3)	0.2844
Treated hypertriglyceridaemia	11 (1.7)	23 (1.2)	0.2890
Inflammatory disease	5 (0.8)	26 (1.3)	0.2607
Myocardial infarction	5 (0.8)	9 (0.4)	0.3576
Type 1 diabetes	5 (0.8)	3 (0.1)	0.0260*
Stroke	4 (0.6)	15 (0.7)	1.0000
Angina pectoris	3 (0.5)	16 (0.8)	0.4366
Lower limb arthritis	–	7 (0.4)	0.2035
Parkinson's disease	–	1 (0.1)	1.0000
Skin diseases[a]			
Psoriasis	90 (13.7)	197 (9.7)	<0.0001****
Atopic dermatitis	83 (12.4)	207 (10.3)	0.0008***
Alopecia areata	28 (4.3)	48 (2.4)	0.0039**

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$; ****$p < 0.0001$.
[a]2018 questionnaire.

represented. The mean (SD) age in the vitiligo population was 51.2 (12.5) years, and the mean (SD) age of onset was 25.1 (15.5) years; 63% of patients were diagnosed before age 30 years. Most patients were diagnosed by a dermatologist (83.5%), with the remaining patients diagnosed by a general practitioner (14.1%) or another specialist (6.3%). The mean (SD) disease duration was 32.6 (15.7) years. Vitiligo lesions were on visible areas (i.e. face and hands) in 81.1% of patients; 62.4% of patients had facial vitiligo (Figure 2a). The mean (SD) SA-VES score was 6.0% (12.7%). Most patients (85.8%) had vitiligo on <10% of their body (mean [SD] SA-VES score, 1.93% [0.95%]), per self-assessment, although extensive vitiligo was reported in each body region for some patients (Figure 2b).

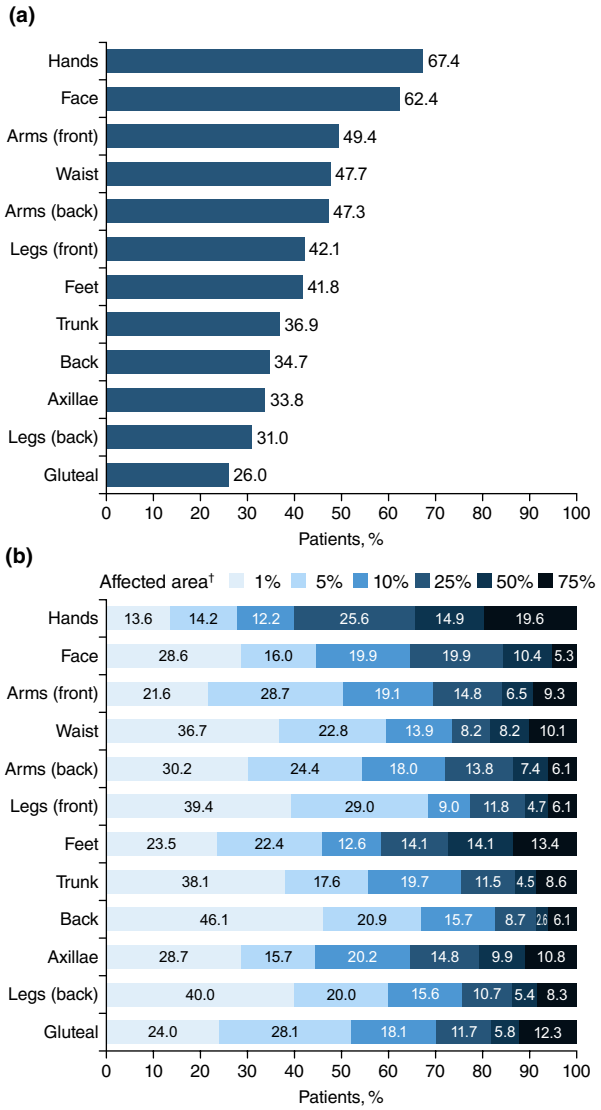

FIGURE 2 Vitiligo lesions by (a) anatomic location and (b) extent of vitiligo within each anatomic location. †Patients were asked to score the extent of their vitiligo lesions in 12 body regions by selecting from a series of images showing six different extents of vitiligo in each body region.

For most patients (74.9%), vitiligo occurred equally on both sides of the body (i.e. nonsegmental vitiligo). The majority of patients (56.4%) had stable or slow progressive vitiligo.

Patients assessed their vitiligo severity as a mean (SD) of 3.9 (2.4) on a scale of 1–10, with 10 being extremely severe. Lesions on visible areas and the extent of vitiligo contributed to patients' assessment of severity (Table 3). Significantly higher severity scores were observed in patients with >5% versus ≤5% BSA (mean [SD], 6.4 [2.1] vs. 3.1 [1.9], respectively; $p < 0.0001$) as well as in patients with lesions on visible areas versus other areas (mean [SD], 4.3 [2.4] vs. 2.2 [1.5], respectively; $p < 0.0001$); no difference was observed among patients with dark (types IV–VI)

TABLE 3 Disease characteristics of patients with vitiligo.

Characteristic	Vitiligo ($n = 681$)
Age at onset, years	$n = 551$
Mean (SD)	25.1 (15.5)
Median (range)	22.0 (0–70.0)
Family history of vitiligo, *n* (%)[a]	95 (14.4)
Vitiligo severity score[b]	$n = 673$
Mean (SD)	3.9 (2.4)
Median (range)	3.0 (1.0–10.0)
Disease duration, years	
Mean (SD)	32.6 (15.7)
Median (range)	33.0 (0–75.0)
Criteria for severity, *n* (%)	$n = 673$
Lesion on visible area	400 (59.4)
Lesion size	387 (57.5)
Lesion location	331 (49.2)
Impossibility to mask lesion	210 (31.2)
Speed of evolution	107 (15.9)
SA-VES	$n = 632$
Mean (SD)	6.0 (12.7)
Median (range)	1.4 (0–73.9)
Progression, *n* (%)	$n = 679$
Slow and progressive	194 (28.6)
No progression	189 (27.8)
A small number of light-coloured plaques or lesions at first, followed by stabilization (a period without progression) and then rapid progression later in life	100 (14.7)
Rapid progression at disease onset followed by stabilization	94 (13.8)
Rapid progression with intermittent periods of lesion progression and stabilization	44 (6.5)
Continuous rapid progression from the beginning without stabilization	21 (3.1)
Other	37 (5.4)

Abbreviation: SA-VES, Self-Assessment Vitiligo Extent Score.

[a]Data missing from 20 patients.

[b]Score range, 0–10 (higher scores indicate greater severity).

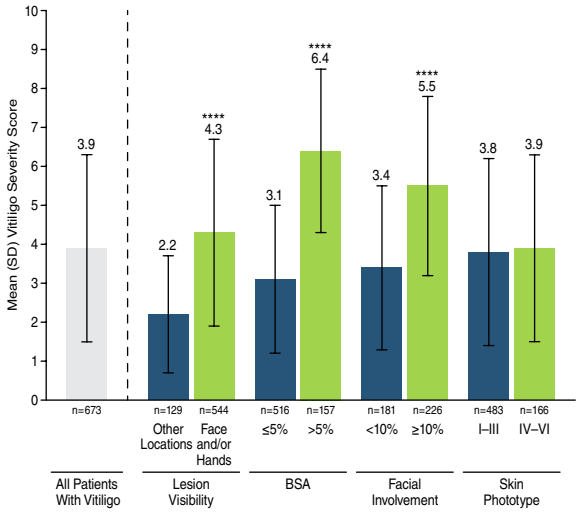

FIGURE 3 Vitiligo severity by clinical characteristic subgroup. BSA, body surface area. ****$p < 0.0001$.

versus fair (types I–III) skin phototypes (Figure 3). Patients with ≥10% facial involvement also reported significantly higher severity scores versus patients with <10% facial involvement (mean [SD], 5.5 [2.3] vs. 3.4 [2.1], respectively; $p < 0.0001$).

General health and QoL

Patients with vitiligo had slightly worse (albeit statistically significant) self-assessed general health versus controls (mean [SD], 2.7 [1.3] vs. 2.6 [1.2], respectively; $p = 0.03$), and fewer patients were very satisfied with their lives (38.9% vs. 45.0%; $p = 0.03$) and work (35.2% vs. 43.6%; $p = 0.03$). Similarly, fewer patients were satisfied or very satisfied with their sexual lives (69.7% vs. 75.6%; $p = 0.04$). Treated depression was more common in patients with vitiligo versus controls (18.2% vs. 14.6%, respectively; $p = 0.03$). In addition, significantly more patients with vitiligo versus controls had a CES-D score ≥ 19, a validated threshold for assessing depression symptoms in the French population[17] (17.5% vs. 14.3%, respectively; $p = 0.04$).

Mean scores of QoL assessments indicated that vitiligo had no effect or mild effect on QoL for most patients, based on previously reported thresholds of severity.[18] QoL was significantly worse among patients with higher BSA involvement, lesions on visible areas or higher facial involvement (Table 4). Furthermore, the differences between the subgroups were greatest with the vitiligo-specific assessments (VitiQoL and VIPs) compared with the general skin-specific instruments (DLQI and PUSH-D), which showed smaller differences, and the generic instrument (EQ-5D-5L), which showed negligible difference.

Therapeutic management

Most patients (83.8%) did not receive any prescribed vitiligo treatment in 2019 (i.e. <3 deliveries of dermocorticoids, no deliveries of tacrolimus and no phototherapy sessions). The most common treatments were oral corticoids (17.3%), dermocorticoids (14.2%) and tacrolimus (2.8%); <1% of patients received phototherapy. Nearly half of patients with vitiligo (43.4%) reported purchasing nonprescription treatment in the last 12 months; of these purchases, 92.2% were for sunscreen, 33.7% for makeup, 25.9% for other creams, 17.7% for food supplements and vitamins and 6.5% for depigmenting creams.

DISCUSSION

This cross-sectional study summarizes the prevalence, disease characteristics, burden and QoL of patients with vitiligo in a real-world setting in France compared with matched control participants. The large size of the CONSTANCES cohort is a strength of the study and allows the results to be generalized at the national level.

The prevalence of vitiligo observed in this study (0.71%) is comparable to that seen in other studies in France.[4,19] However, it is important to note that prevalence depends on the criteria used to define patients. Herein, we used stringent criteria. Using a less-conservative approach, such as the inclusion of patients who reported having vitiligo in 2018, regardless of confirmation in 2022 or physician diagnosis, would likely have resulted in a higher prevalence. The early age of onset (<30 years) observed in most patients is also concordant with published data.[2] Patients with vitiligo were matched using a propensity score to participants in the CONSTANCES cohort who did not report having vitiligo, which allowed for assessment of disease burden compared with a representative control group. Patients with vitiligo reported significantly reduced general health as well as reduced satisfaction with life, work and sexual life compared with matched controls. Significant differences in the prevalence of some comorbidities (i.e. thyroid disease, type 1 diabetes, atopic dermatitis, psoriasis and depression with treatment) were observed in patients with vitiligo versus controls, consistent with other studies.[3,20,21]

Although approximately 85% of patients with vitiligo had <10% BSA involvement, patients reported moderate vitiligo severity. Vitiligo lesions on visible areas as well as the extent of vitiligo were cited by patients as the biggest contributors towards patient-assessed vitiligo severity. Consistent with this finding, patients with vitiligo on visible areas or >5% BSA involvement had significantly higher (i.e. worse) severity scores compared with patients with vitiligo on other areas or ≤5% BSA, respectively. Patients with ≥10% facial involvement (i.e. higher extent in visible areas) had significantly higher severity scores versus patients with <10% facial involvement.

TABLE 4 Quality of life scores.

	All patients with vitiligo ($n = 681$)	Lesion visibility		Extent of vitiligo		Extent of facial involvement		Skin phototype	
		Vitiligo on other locations ($n = 129$)	Vitiligo on face and/or hands ($n = 552$)	≤5% BSA ($n = 521$)	>5% BSA ($n = 160$)	<10% ($n = 184$)	≥10% ($n = 229$)	I–III ($n = 488$)	IV–VI ($n = 167$)
EQ-5D-5L[a]	$n = 672$	$n = 128$	$n = 544$	$n = 514$	$n = 158$	$n = 182$	$n = 226$	$n = 484$	$n = 163$
Mean (SD)	0.96 (0.08)	0.97 (0.10)	0.96*** (0.08)	0.96 (0.07)	0.94* (0.13)	0.97 (0.06)	0.94 (0.10)*	0.96 (0.07)	0.95 (0.10)
Median (range)	0.98 (0.16–1.00)	1.00 (0.16–1.00)	0.98 (0.27–1.00)	0.98 (0.33–1.00)	0.98 (0.16–1.00)	0.98 (0.55–1.00)	0.98 (0.27–1.00)	0.98 (0.28–1.00)	0.98 (0.27–1.00)
DLQI[b]	$n = 580$	$n = 110$	$n = 470$	$n = 444$	$n = 136$	$n = 167$	$n = 195$	$n = 416$	$n = 146$
Mean (SD)	4.7 (2.9)	3.5 (1.1)	5.0**** (3.1)	4.0 (2.0)	6.8**** (4.1)	4.4 (2.5)	6.0**** (3.8)	4.7 (2.8)	4.7 (2.9)
Median (range)	4.0 (2.0–22.0)	3.0 (2.0–11.0)	4.0 (2.0–22.0)	3.0 (2.0–18.0)	6.0 (2.0–22.0)	3.0 (2.0–22.0)	4.0 (2.0–20.0)	4.0 (2.0–22.0)	4.0 (2.0–18.0)
≥11, *n* (%)	31 (5.3)	1 (0.9)	30**** (6.4)	9 (2.0)	22**** (16.2)	5 (3.0)	24*** (12.3)	21 (5.0)	7 (4.8)
PUSH-D[c]	$n = 622$	$n = 120$	$n = 502$	$n = 480$	$n = 142$	$n = 171$	$n = 207$	$n = 449$	$n = 148$
Mean (SD)	2.8 (5.9)	0.8 (2.9)	3.3**** (6.3)	2.0 (5.0)	5.6**** (7.5)	2.0 (4.0)	5.3**** (8.0)	2.6 (5.6)	3.3 (6.5)
Median (range)	0 (0–44.0)	0 (0–18.0)	0 (0–44.0)	0 (0–44.0)	2.0 (0–34.0)	0 (0–20.0)	1.0 (0–44.0)	0 (0–44.0)	0 (0–29.0)
VIPs[d]	$n = 677$	$n = 129$	$n = 548$	$n = 517$	$n = 160$	$n = 184$	$n = 227$	$n = 487$	$n = 164$
Mean (SD)	11.6 (14.2)	3.6 (5.2)	13.5**** (15.0)	8.2 (10.4)	22.3**** (19.0)	9.9 (12.4)	19.2**** (17.1)	11.0 (14.1)	12.3 (13.8)
Median (range)	6.0 (0–84.0)	1.0 (0–24.0)	8.0 (0–84.0)	5.0 (0–55.0)	17.0 (0–84.0)	5.0 (0–84.0)	14.0 (0–84.0)	6.0 (0–84.0)	7.0 (0–65.0)
VitiQoL[e]	$n = 661$	$n = 124$	$n = 537$	$n = 503$	$n = 158$	$n = 179$	$n = 225$	$n = 480$	$n = 162$
Mean (SD)	14.0 (17.1)	3.3 (5.6)	16.5**** (17.9)	9.9 (13.0)	27.0**** (21.7)	12.4 (14.9)	23.5**** (20.8)	13.6 (16.7)	14.0 (17.6)
Median (range)	7.0 (0–89.0)	1.0 (0–42.0)	9.0 (0–89.0)	6.0 (0–72.0)	21.0 (0–89.0)	7.0 (0–89.0)	17.0 (0–87.0)	7.0 (0–89.0)	7.0 (0–69.0)

Abbreviations: BSA, body surface area; DLQI, Dermatology Life Quality Index; EQ-5D-5L, EuroQoL 5-Dimensions 5-Levels questionnaire; PUSH-D, Patient Unique Stigmatization Holistic Tool in Dermatology; VIPs, Vitiligo Impact Patient scale; VitiQoL, Vitiligo-specific Quality of Life.

* $p < 0.05$; *** $p < 0.001$; **** $p < 0.0001$.

[a]Score range, 0–1 (lower scores indicate greater burden).

[b]Score range, 0–30 (higher scores indicate greater impairment).

[c]Score range, 0–85 (higher scores indicate greater stigma).

[d]Score range, 0–95 (higher scores indicate greater burden).

[e]Score range, 0–90 (higher scores indicate greater burden).

To further assess disease burden, a comprehensive set of PRO assessments, including generic, skin-specific and vitiligo-specific instruments, were used in this study. Similar to the patient-assessed severity data, patients with visible lesions, >5% BSA involvement or ≥10% facial involvement had significantly higher QoL impairment and stigmatization, consistent with other studies.[3,18] Skin phototype (i.e. dark vs. fair skin) did not significantly affect patient-perceived disease burden, although mean QoL scores were slightly higher for darker skin (indicating worse impairment) for some instruments. A lack of significance of skin phototypes on QoL has also been reported in other studies.[22–24] Interestingly, the differences between lesion location, BSA and facial involvement subgroups were most apparent with the VitiQoL and VIPs, which are specifically designed for patients with vitiligo. Differences were present but less apparent with general skin PROs (i.e. DLQI and PUSH-D) and were negligible with the generic EQ-5D-5L. These findings are likely attributable to the nature of the questions included in these instruments. For example, although an impaired QoL was identified using the DLQI, it is not specific enough to capture the nuances of the vitiligo disease burden.[25] Furthermore, some items in the DLQI focus on symptomatology, which is less relevant in vitiligo.[15] Taken together, these findings highlight the need for the use of vitiligo-specific instruments to further assess disease burden, particularly in prospective clinical trials evaluating the efficacy of vitiligo treatments.

Findings from this analysis also suggest that most patients with vitiligo are not receiving treatment. In 2019, 84% of patients did not receive any prescribed treatments (i.e. dermocorticoids, tacrolimus and phototherapy). These results suggest that additional education about treatment options and expected outcomes is needed for physicians and patients. Before the 2023 approval of ruxolitinib cream for adults and adolescents aged ≥12 years with nonsegmental vitiligo with facial involvement, there were no approved repigmentation therapies in Europe, which likely contributed to the low percentage of patients who received prescriptions, although European recommendations proposed off-label treatments.[6] Indeed, results from the VALIANT study indicated that 65% of patients with vitiligo (including 76% in France) were informed that their vitiligo could not be treated.[26,27] These findings highlight the lack of physician education concerning vitiligo treatment.

Regarding study limitations, there is an intrinsic potential for selection bias typical for PRO studies. Older patients (aged ≥69 years) were underrepresented in this study, although because vitiligo is often diagnosed before 30 years of age and thus is not specific to an elderly population, this limitation is unlikely to introduce bias into the findings of the study. Additionally, patients with vitiligo in this study had a minimum disease duration of 4 years (i.e. the time between questionnaires), so this analysis does not account for the disease burden in patients with new diagnoses, which may be higher. Additionally, the indication for prescribed treatment was not captured, and these treatments are often used for other skin conditions, which are common comorbidities in patients with vitiligo (i.e. atopic dermatitis); thus, the proportion of patients receiving treatment specifically for vitiligo may be lower than reported in this analysis. Identification of patients relied on self-reported physician diagnoses of vitiligo. Although this approach limits the potential inclusion of patients with incorrect diagnoses, some patients with vitiligo who did not receive a consult from a physician, as well as patients who were diagnosed with vitiligo between 2018 and 2022, may have been excluded.

In summary, this study highlights the substantial number of patients living with vitiligo in France and the effect of vitiligo on their QoL during their daily lives. Patients with visible vitiligo lesions or higher BSA involvement have significantly impaired QoL. Despite the reduced QoL, most patients in France are not receiving vitiligo treatment, thus underscoring the need for new effective treatment options. The effect of the recent approval of ruxolitinib cream in Europe on the observed suboptimal treatment remains to be seen. Furthermore, additional education for physicians and patients is needed regarding treatment options and expectations. Finally, appropriate vitiligo-specific QoL assessment tools should be used to evaluate and manage the disease burden.

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CONFLICT OF INTEREST STATEMENT

KE has served as a consultant for AbbVie, Incyte Corporation, Pfizer, Pierre Fabre Pharmaceuticals, Sanofi and Viela Bio. JS has received grants and/or honoraria from AbbVie, Bristol Myers Squibb, Calypso Biotech, Eli Lilly, Incyte Corporation, LEO Pharma, Novartis, Pfizer, Pierre Fabre, Sanofi, Sun Pharmaceuticals and Viela Bio, and has patents on MMP9 inhibitors and uses thereof in the prevention or treatment of a depigmenting disorder and a three-dimensional model of depigmenting disorder. ADS and JF are employees and shareholders of Incyte Biosciences France. NP has received expert fees from Incyte Corporation and AbbVie during the last 5 years. AL is a member of the Board of Directors of the French Association of Vitiligo and has nothing to declare. CD is an employee and shareholder of Incyte Biosciences International Sàrl. CE, CN and SB are employees of CEMKA, which received an unconditional grant from Incyte Corporation to conduct the analysis of this study. TP has received grants and/or honoraria from AbbVie, ACM Pharma, Almirall, Amgen, Astellas, Bristol Myers Squibb, Calypso, Celgene, Galderma, Genzyme/Sanofi, GlaxoSmithKline, Incyte Corporation, Janssen, LEO Pharma, Eli Lilly, Novartis, Pfizer, Sun Pharmaceuticals, UCB and Vyne Therapeutics; is the cofounder of YUKIN Therapeutics; and has patents on WNT agonists and GSK3b antagonists for repigmentation of vitiligo and on the use of CXCR3B blockers in vitiligo.

DATA AVAILABILITY STATEMENT

Access to individual participant-level data is not publicly available for this study.

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