

Living with vitiligo: results from a national survey indicate differences between skin phototypes

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DEAR EDITOR, Vitiligo, an acquired, idiopathic skin disease characterized by a generally progressive loss of inherited skin colour, has an estimated worldwide prevalence of 0.5–1%.^{1,2} Although vitiligo is more noticeable in individuals with dark skin, the prevalence is similar to that in the overall population.³

Despite not being life threatening, vitiligo is a serious skin disorder and the overall disease burden in individuals with vitiligo is often underestimated.³ The current study determined the burden, in the broadest sense (including impact on quality of life, self-perceived stress and self-image) of vitiligo on daily life and, in particular, assessed differences in the perception of vitiligo and its management in fair vs. dark skin phototypes.

We conducted a cross-sectional monocentric study in 300 patients with vitiligo, within the framework of developing a new specific vitiligo burden questionnaire. Consulting dermatologists recorded patient demographic/clinical characteristics, and classified patients as having 'fair skin' (phototype I–III) or 'dark skin' (phototype IV–VI). This study was approved by the Commission Nationale Informatique et Libertés and by the local ethics committee of the University Hospital of Bordeaux.

The burden of vitiligo was evaluated via a conceptual vitiligo-burden-specific questionnaire (developed by the authors) and several validated assessment tools: Short Form-12,⁴ Dermatology Life Quality Index (DLQI),⁵ PCV-Metra (Prévention Cardio-Vasculaire en Médecine du Travail)⁶ and Body Image States Scale.⁷ The conceptual vitiligo questionnaire, created after conducting face-to-face interviews between patients with vitiligo ($n = 25$), experts in questionnaire design and psychology, and physicians involved in vitiligo, consisted of 35 questions, each with seven possible responses: 'all the time', 'very often', 'often' (collectively 'yes'), 'sometimes', 'rarely', 'never' and 'not applicable' (collectively 'no').

Three hundred individuals with vitiligo (72% female; mean age 48.9 ± 16.2 years, range 15–87) were classified as having fair ($n = 234$) or dark ($n = 66$) skin. The majority of patients classified with dark skin were of Middle Eastern, Caribbean or Indian ethnicity.

Vitiligo most commonly affected the hands (85% of patients), wrists (69%), armpits (62%), feet (62%), elbows (61%) and mouth (59%). The face (76%) and hands (54%)

were the most troublesome body areas affected by vitiligo. Overall, respectively 29%, 42%, 22%, 6% and 2% of patients reported < 5%, 5–10%, 10–25%, 25–50% and > 50% of their body area affected by vitiligo. There were no between-group differences for these parameters.

More patients with dark skin than fair skin reported being satisfied with their support/management (34% vs. 20%, $P = 0.046$). However, 47% of fair-skinned patients replied 'undecided/don't know' in response to 'are you satisfied with your treatment?'; 73% of all patients were 'undecided/not treated', with < 10% of respondents answering 'yes'. The majority (91%) of patients reported following their physician's prescription 'most often/occasionally', with < 20% of patients self-medicating.

Patients in both groups demonstrated impaired quality of life, self-perceived stress levels and self-image (Table 1). Patients with dark skin reported higher DLQI scores than those with fair skin (Table 1; $P = 0.049$). The responses obtained with the conceptual vitiligo questionnaire are shown by skin phototype in Table S1 (see Supporting Information).

Twenty-two of 42 factors assessed by univariate analysis were retained at the predetermined $P < 0.15$ level (Table S2; see Supporting Information). Multivariate analysis demonstrated three factors that were significantly associated with skin phototype (Table 2). For patients with dark skin, significant factors were 'my vitiligo has repercussions on my physical appearance' [odds ratio (OR) 3.41, 95% confidence interval (CI) 1.04–11.13; $P = 0.042$] and 'managing my vitiligo on a daily basis is a burden' (OR 3.09, 95% CI 1.07–8.95; $P = 0.037$). In contrast, 'my vitiligo puts me at greater risk for skin cancer' (OR 0.37, 95% CI 0.15–0.95; $P = 0.039$) was significantly associated with a higher burden in fair-skinned individuals. The latter perception is interesting in light of studies indicating that patients with vitiligo have a decreased risk of melanoma and nonmelanoma skin cancer;^{8,9} improved patient education by physicians may be warranted in this area.

This study demonstrates that, regardless of skin phototype, patients with vitiligo experience significant disease-related burden and self-perceived stress. Furthermore, although patients with dark skin phototypes perceived some significant differences in the burden of vitiligo on daily life compared with their fair-skinned counterparts, and vice versa, overall self-perceived stress associated with vitiligo was generally similar in patients regardless of skin type.

The current study reinforces outcomes from previous studies,^{10–14} while providing new insights into differences in the

Table 1 Quality-of-life, stress and self-image scale scores in patients with vitiligo by skin phototype

	Fair skin	Dark skin	Total
DLQI			
No. of patients	202	59	261
Mean \pm SD	8.3 \pm 6.2	10.1 \pm 6.3 ^a	8.7 \pm 6.2
Range	0.0–28.0	1.0–23.0	0.0–28.0
Median	7.0	9.0	7.0
SF-12 physical component summary			
No. of patients	217	63	280
Mean \pm SD	55.3 \pm 7.1	55.6 \pm 7.2	55.4 \pm 7.1
Range	31.4–67.7	33.3–68.7	31.4–68.7
Median	57.5	57.4	57.5
SF-12 mental component summary			
No. of patients	217	63	280
Mean \pm SD	39.5 \pm 11.0	36.5 \pm 12.0	38.8 \pm 11.3
Range	13.0–62.1	12.7–62.4	12.7–62.4
Median	39.1	38.1	38.6
PCV-Metra (stress)			
No. of patients	234	66	300
Mean \pm SD	8.5 \pm 3.7	8.9 \pm 3.7	8.6 \pm 3.7
Range	0.0–19.0	1.0–18.0	0.0–19.0
Median	8.0	9.0	9.0
BISS			
No. of patients	220	64	284
Mean \pm SD	20.9 \pm 4.3	20.6 \pm 4.4	20.8 \pm 4.4
Range	6.0–29.0	6.0–30.0	6.0–30.0
Median	22.0	21.0	22.0

DLQI, Dermatology Life Quality Index; SF-12, Short Form-12 questionnaire; PCV-Metra, Prévention Cardio-Vasculaire en Médecine du Travail; BISS, Body Image States Scale. ^aP = 0.049 (Wilcoxon).

daily burden, in the broadest sense, of vitiligo between patients with different skin phototypes. Although the Short Form-12 and DLQI questionnaires provided a general picture of impaired quality of life in patients with vitiligo in our study, they were not specific enough to detect nuances in how patients deal with the overall vitiligo burden. Indeed, it is acknowledged that the DLQI does not measure emotional/psychosocial disease burden.¹⁴ Use of the conceptual vitiligo questionnaire enabled us to identify several specific factors that occurred in significantly more patients with dark skin than fair skin, although stress associated with the burden of vitiligo was similar in all patients regardless of skin phototype. Specifically, whereas fair-skinned patients were more worried about skin cancer occurrence, patients with dark skin expressed greater concern about physical appearance linked to vitiligo burden. Such differences may help clinicians in the psychological management of patients with vitiligo.

The classification of patients with vitiligo into two categories according to dermatologist-determined skin phototype, rather than by individual ethnicity, limits any possible correlation between vitiligo burden and ethnicity. However, French health authorities do not allow ethnicity data to be recorded. Moreover, individuals classified with dark skin represented

Table 2 Multivariate analysis to evaluate factors associated with vitiligo burden according to skin phototype. Modelled probability: dark skin

Factor ('yes' vs. 'no')	Odds		
	ratio	95% CI	P-value
I feel discouraged because of my vitiligo	0.42	0.16–1.11	0.079
My vitiligo has repercussions on my physical appearance	3.41	1.04–11.13	0.042 ^a
Passing my vitiligo on to my children worries me, makes me anxious	1.02	0.43–2.40	0.97
The looks I get from people because of my vitiligo are hard to bear	1.87	0.67–5.23	0.23
Questions about my vitiligo bother me, disturb me	2.13	0.74–6.17	0.16
I make sacrifices in order to afford my vitiligo treatments	1.54	0.41–5.81	0.52
My reflection in the mirror makes me anxious	1.04	0.35–3.06	0.95
In the evening, once I've applied all the creams, I feel depressed	2.71	0.91–8.03	0.072
Managing my vitiligo on a daily basis is a burden	3.09	1.07–8.95	0.037 ^a
I tend to withdraw into myself because of my vitiligo	2.35	0.68–8.09	0.18
The progression of my vitiligo worries me (makes me anxious)	1.10	0.31–3.85	0.88
The looks in my loved one's eyes are difficult to bear	0.57	0.19–1.66	0.30
I sometimes feel like giving up	0.77	0.26–2.25	0.63
I often tell myself that my life would be very different without vitiligo	2.67	0.93–7.70	0.069
I am ashamed of the consequences of my vitiligo	0.54	0.16–1.77	0.31
My vitiligo has been a problem at job interviews	2.64	0.77–8.98	0.12
I worry that my vitiligo will spread	1.30	0.41–4.16	0.66
My vitiligo puts me at greater risk for skin cancer	0.37	0.15–0.95	0.039 ^a
I dread first meetings because of my vitiligo	0.53	0.15–1.84	0.32
The looks I get from children because of my vitiligo are hurtful	1.63	0.64–4.13	0.30
Applying a treatment every day is a burden	0.96	0.39–2.38	0.93
Dermatology Life Quality Index	0.92	0.83–1.01	0.074

CI, confidence interval. ^aSignificant value.

22% of the study population; future studies in a larger population of individuals with skin phototypes IV–VI would allow evaluation of potential intragroup differences between individuals with these phototypes. The conceptual vitiligo questionnaire was created for preliminary descriptive purposes in

French nationals with vitiligo, potentially limiting generalizability to wider geographical populations. Ongoing studies will refine, validate and translate the conceptual vitiligo questionnaire to ensure interpretability across a wide range of languages and cultures.

The current study provides valuable information on the burden of vitiligo in patients with different skin phototypes. In particular, the study indicates that although patients with dark or fair skin phototypes cope with vitiligo differently, all patients with vitiligo appear to be equally stressed by their condition. According to patient and clinician consensus, the burden of vitiligo is considered one of the core outcomes for vitiligo clinical trials.¹⁵ An improved understanding of the daily burden experienced by patients with vitiligo may assist dermatologists to focus their efforts on patients at particular risk of substantial impairment.

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References

- Ezzedine K, Eleftheriadou V, Whitton M, van Geel N. Vitiligo. *Lancet* 2015; **386**:74–84.
- Taïeb A, Alomar A, Böhm M et al. Guidelines for the management of vitiligo: the European Dermatology Forum consensus. *Br J Dermatol* 2013; **168**:5–19.
- Bhandarkar SS, Kundu RV. Quality-of-life issues in vitiligo. *Dermatol Clin* 2012; **30**:255–68, viii.
- Ware J, Kosinski M, Keller S. A. 12-item short-form health survey. Construction of scales and preliminary tests of reliability and validity. *Med Care* 1996; **34**:220–33.
- Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI) – a simple practical measure for routine clinical use. *Clin Exp Dermatol* 1994; **19**:210–16.
- Consoli SM, Taine P, Szabason F et al. [Development and validation of a perceived stress questionnaire recommended as a follow-up indicator in occupational medicine]. *Encephale* 1997; **23**:184–93 (in French).
- Cash TF, Fleming EC, Alindogan J et al. Beyond body image as a trait: the development and validation of the Body Image States Scale. *Eat Disord* 2002; **10**:103–13.
- Teulings HE, Overkamp M, Ceylan E et al. Decreased risk of melanoma and nonmelanoma skin cancer in patients with vitiligo: a survey among 1307 patients and their partners. *Br J Dermatol* 2013; **168**:162–71.
- Paradisi A, Tabolli S, Didona B et al. Markedly reduced incidence of melanoma and nonmelanoma skin cancer in a nonconcurrent cohort of 10,040 patients with vitiligo. *J Am Acad Dermatol* 2014; **71**:1110–16.
- Kostopoulou P, Jouary T, Quintard B et al. Objective vs. subjective factors in the psychological impact of vitiligo: the experience from a French referral centre. *Br J Dermatol* 2009; **161**:128–33.
- Shah R, Hunt J, Webb TL, Thompson AR. Starting to develop self-help for social anxiety associated with vitiligo: using clinical significance to measure the potential effectiveness of enhanced psychological self-help. *Br J Dermatol* 2014; **171**:332–7.
- Lilly E, Lu PD, Borovicka JH et al. Development and validation of a vitiligo-specific quality-of-life instrument (VitiQoL). *J Am Acad Dermatol* 2013; **69**:e11–18.
- Gupta V, Sreenivas V, Mehta M et al. Measurement properties of the Vitiligo Impact Scale-22 (VIS-22), a vitiligo-specific quality-of-life instrument. *Br J Dermatol* 2014; **171**:1084–90.
- Linthorst Homan MW, Spuls PI, de Korte J et al. The burden of vitiligo: patient characteristics associated with quality of life. *J Am Acad Dermatol* 2009; **61**:411–20.
- Eleftheriadou V, Thomas K, van Geel N et al. Developing core outcome set for vitiligo clinical trials: international e-Delphi consensus. *Pigment Cell Melanoma Res* 2015; **28**:363–9.

Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Table S1. Responses to individual questions in the conceptual vitiligo questionnaire, by patient skin phototype.

Table S2. Univariate analysis to evaluate factors associated with vitiligo burden according to skin phototype.

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