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The patient's perspective on the burden of psoriasis: findings based on the ROCQ, an online survey

Background: Psoriasis is a common chronic skin disease, with well-characterised impact on quality-of life, however, no information is available on the lifetime impact of psoriasis on patients' lives. **Materials & Methods:** This descriptive cross-sectional web-based survey of patients with psoriasis, recruited from an online patient community, was conducted in France in 2021. Established questionnaires (Major Life-Changing Decision Profile-MLCDP, Dermatology Life Quality Index-DLQI, Hospital Anxiety and Depression Scale [HADS]), CAGE and BRIEF-COPE) were administered together with specially created questions. **Results:** In total, 301 adult patients (mean age: 46.9 years; 56% women; mean disease duration: 20.3 years) participated in the study. The MLCDP showed that a mean of 9.4 life-changing decision items were affected; the most frequently cited domains being social life ($n=258$; 85.7%) and physical activity ($n=226$; 75.1%). In addition, 183 participants (60.7%) declared at least moderate impact of their psoriasis on their quality of life (score ≥ 6), with a median DLQI score of 7 [IQR: 3-13]. Impact on activities of daily living, such as social life, physical activities and marital relationships, was reported by over 50% of participants. Moreover, 107 (35.5%) declared being satisfied and 66 (21.9%) very satisfied with care. Over 50% of participants reported stigma related to being considered to have a contagious disease ($n=182$) or being unhygienic ($n=163$) and undesirable ($n=167$). Finally, 104 participants (34.6%) presented with clinically relevant anxiety and 32 (10.6%) clinically relevant depression (score ≥ 11) based on the HADS. **Conclusion:** Psoriasis carries a high psychological burden and has a strong long-term impact on social functioning.

Key words: psoriasis, patient-reported outcome measures, MLCDP, psychological burden, social functioning, cumulative life course impairment

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Psoriasis is a common, chronic, non-communicable, immune-mediated inflammatory skin disease, with no clear cause or cure. Prevalence varies between countries and geographical regions, being highest in high-income countries and in regions with older populations [1, 2]. With at least 100 million individuals affected worldwide, psoriasis is a serious global problem and the disease has been declared as a major global health problem by the World Health Organization (WHO) in 2013, and as a serious non-communicable disease (NCD) in the World Health Assembly resolution WHA67.9 in 2014 [3]. In France, psoriasis concerns 2.4 million people [4].

Psoriasis has an unpredictable course, with outbreaks being influenced by a number of external triggers. Due to the visibility of the lesions, affected individuals may experience significant stigma [3]. In addition, effective treatment options are limited and long-term

management of the disease is challenging to achieve. For these reasons, psoriasis may have a considerable negative impact on patients' lives and well-being. Most patients with psoriasis report a significant impact of their disease on their social life, social interaction with others and health-related quality of life (HR-QoL) [5-7].

In addition to this immediate impact of psoriasis on patient well-being, the disease may also affect the long-term course of patients' lives, with repercussions that accumulate over a lifetime (and may well be irreversible), that interfere with individuals' full development potential and alter their perspectives with respect to the goals which they would have set themselves in the absence of disease [5]. These ideas have been formalised into the concept of cumulative life course impairment (CLCI) and have been the focus of much discussion both for psoriasis and for other chronic skin disorders over recent years [8-14]. Kimball *et al.* have proposed that CLCI

may arise in patients with psoriasis due to the burden of stigma, concomitant physical and psychological comorbidities, inappropriate coping mechanisms and external factors [8]. However, to the best of our knowledge, no data have been generated on CLCI in dermatological diseases to date. In this respect, the Major Life-Changing Decisions Profile questionnaire (MLCDP) has been developed recently in order to measure the impact of disease on important decisions in patients' lives, such as career choice, having children, marriage, divorce, early retirement and moving abroad [15]. Unlike conventional patient reported outcome measures (PROMs), which focus on current perceptions of the patient's life, the MLCDP was developed to investigate the lifetime impact of disease, consistent with the notion of CLCI [15]. The primary objective of the current study was to collect data from patients with psoriasis using the MLCDP as a proxy measure of CLCI. Secondary objectives were to describe other aspects of the subjective experience of psoriasis using other PROMs and investigate variables associated with CLCI.

Methods

The ROCQ study was a descriptive cross-sectional web-based survey of adult patients with self-reported plaque psoriasis resident in France. Recruitment of participants was conducted over a six-week period between 6th May 2021 and 18th June 2021.

Data source

Carenity (<https://www.carenity.com/>) is an online patient community for people with chronic diseases, or their relatives or carers [16, 17]. Experiences can be shared by patients and their caregivers in more than 1,200 disease-specific communities, and they can also share information on the disease and ask for information or advice. Online surveys are regularly proposed to the community on various aspects of disease perceptions. At the time of the study, the Carenity psoriasis community had around 3,300 members in France.

Study population

The study population included adult patients living in France with a diagnosis of plaque psoriasis. Participants were either members of the Carenity community or users of Carenity social media (such as FacebookTM or TwitterTM). Each adult registered on the French Carenity psoriasis platform was invited to participate in the study by electronic mail and private messages on the platform, and the study was advertised *via* banners or posts on the Carenity forum website and social media. The target sample size was prespecified at 300 participants. To be eligible, participants were required to be adults (≥ 18 years at the time of inclusion), live in France, and have received a diagnosis of plaque psoriasis (which could include those with psoriatic arthritis). In order to limit the survey to patients with clinically relevant symptoms, the disease was required either to have affected $>10\%$ of the body surface at least once since the onset

of symptoms, as reported by the patient, or to have required prescription of a systemic treatment or phototherapy.

Patients who reported exclusively other psoriasis types, such as inverse psoriasis, pustular psoriasis, guttate psoriasis or erythrodermic psoriasis, were excluded as were patients who did not, or could not, report the percentage of their current body surface affected by psoriasis.

Study questionnaire

The study questionnaire was developed in collaboration with a Scientific Committee composed of two clinical dermatology experts (APV, NQ). The questionnaire was also reviewed by five patients with plaque psoriasis and their comments were taken into consideration for finalisation of the document. The validated questionnaire consisted of a total of 38 questions and took, on average, 20 to 30 minutes to complete. The questionnaire was then dispatched online to all patients who had accepted to participate, either on the Carenity platform or via social media.

The questionnaire collected sociodemographic data (age and gender) and disease characteristics (history and severity, and treatments used). The severity of psoriasis was self-rated. The impact of psoriasis on participants' lives was assessed using established questionnaires (MLCDP, DLQI [18], HADS [19], CAGE [20] and BRIEF-COPE [21]), administered in their validated French translations. The Major Life-Changing Decision Profile (MLCDP) evaluates the impact of disease on life-changing events (32 items) using 5-point Likert scales (no influence or not applicable/slight influence/moderate influence/strong influence/very strong influence) [7, 15, 22, 23]. The DLQI (Dermatology Life Quality Index) consists of 10 items (Q1 to Q10) each rated on a four-point Likert scale evaluating the impact of skin diseases on quality of life (QoL) [18]. The HADS (Hospital Anxiety and Depression Scale) [19] is a 14-item questionnaire assessing severity of symptoms of anxiety (seven items) and depression (seven items), each scored on a 4-point Likert scale; a score over 11 for either corresponds to clinically relevant anxiety or depression. The CAGE questionnaire comprises four "yes/no questions" as a screening tool to identify potentially problematic alcohol consumption in the general population [20]. Two positive answers or more are considered to indicate a high probability of alcohol abuse. The BRIEF-COPE is a multidimensional coping inventory to assess the different ways in which people respond to stress. It includes 28 items, each scored on a 4-point Likert scale [21]. These items are assigned empirically to one of two dimensions (approach coping strategies and avoidance coping strategies) identified in the factor analysis of the BRIEF-COPE performed during the psychometric validation of the French version of the questionnaire [24]. Stigma was evaluated using a questionnaire developed previously for use in psoriasis patients in Germany [25] and translated into French for the purposes of the study. This questionnaire consisted of six items assessed on a 4-point Likert scale [25].

Specific questions created for the purposes of this study addressed the satisfaction of participants with current care and their perceptions on social isolation, activities of daily

life affected by psoriasis, addictive behaviours and any use of psychotropic medication or psychotherapy. (*supplementary table 1*). Finally, participants were invited to rate two personality traits on a 10-point visual analogue scale. The first scale distinguished combativeness (score 0) from resignation (score 10) and the second distinguished optimism (score 0) from pessimism (score 10).

Statistical analysis

Due to the observational design of the study and its objective, no statistical hypotheses were tested and the data analysis was descriptive in nature. Confidence intervals and *p* values from statistical analyses were used to assess between-group differences. Categorical variables are presented as frequency counts and percentages and continuous variables are summarised as mean values with their standard deviations (SD) or median values with their interquartile ranges (IQR), as appropriate. The relationship between MLCDP scores and other study variables was assessed using the Pearson correlation coefficient (*r*) for continuous variables and the Student or Wilcoxon tests for categorical variables. Analyses were conducted using Statistical Software R (version 3.5.2).

Ethics

The study was conducted in accordance with ICH Good Epidemiological Practice guidelines and approved by the relevant French Ethics committee (CPP Sud Méditerranée III). Patients participating in the study provided explicit informed consent to the collection, handling and documentation of their personal and health data. Participants received no incentives to participate in the study. Participation was voluntary.

Results

Study participants

Overall, 301 adult patients participated in the study. Their characteristics are presented in *table 1*. The mean age of the participants was 46.9 years and 56% were women. The mean age at first symptoms was 26.7 years and the mean disease duration 20.3 years. Around one quarter of participants had also received a diagnosis of psoriatic arthritis. Of the 301 participants, only 9% had joined a patient advocacy group. At the time of the survey, the proportion of the total body surface affected by psoriasis was most frequently between 3% and 10% (*n* = 137; 45.5%), (*table 1*). The most frequently affected areas were the scalp (68%), elbows (53%), knees (44%), hands (35%) and forearms (34%) (*figure 1*), with 77% (*n* = 233) of participants reporting at least one visible area affected (*table 1*). More than 40% of participants received at least one biological therapy (43.2%) or immunosuppressant drug (41.2%) to treat their psoriasis; 8% had received more than two treatments since diagnosis.

Table 1. Characteristics of study participants.

	<i>n</i> = 301
Current age (mean [95%CI]; years)	46.9 [45.5 – 48.3]
Gender (% women)	170 (56.0%)
Body mass index (mean [95%CI]; kg/m ²)	26.5 [25.8 – 27.1]
Underweight (<18.5)	4 (1.3%)
Normal (18.5-25)	140 (46.5%)
Overweight (25-30)	92 (30.6%)
Obesity (>30)	65 (21.6%)
Family status	
Couple with children	181 (60.1%)
Alone without children	48 (15.9%)
Couple without children	46 (15.3%)
Alone with children	26 (8.7%)
Age at first symptoms (mean [95%CI]; years)	26.7 [25.2 – 28.1]
Time elapsed since the first symptoms (mean [95%CI]; years)	20.3 [18.6 – 21.9]
Diagnosis	
Psoriasis only	220 (73.1%)
Psoriasis with psoriatic arthritis	81 (26.9%)
Extent of psoriatic lesions	
• <i>Current affected body surface</i>	
Less than 3%	80 (26.6%)
3-10%	137 (45.5%)
11-30%	64 (21.3%)
More than 30%	16 (5.3%)
Do not know	4 (1.3%)
• <i>At least one visible area affected</i>	233 (77.4%)
Treatments (including combinations)#	
Biological therapies	130 (43.2 %)
Immunosuppressant drugs	124 (41.2 %)
Phototherapy	67 (22.3 %)
Acitretin	46 (15.3 %)
Apremilast	35 (11.6 %)
None	16 (6.3 %)
Number of treatments received since diagnosis	
0	19 (6.3 %)
1	198 (65.8 %)
2	60 (19.9 %)
3	15 (5.0 %)
4	6 (2.0 %)
5	3 (1.0 %)
Mean number of treatments received (mean [95%CI])	1.3 [1.2;1.4]

Data was presented as (*n*, %) unless otherwise specified. CI: confidence interval; #multiple responses possible.

Impact on major life-changing decisions

The impact of psoriasis on major life-changing decisions was evaluated using the MLCDP. The most frequently cited domains were social life (258; 85.7%) and physical activity (226; 75.1%) and the individual items cited by >50% of participants were ‘*I decided to change my eating habits*’, ‘*I decided to wear different types/colour of clothes/shoes*’, ‘*I decided not to go swimming*’ and ‘*I decided to change to different sporting activities*’ (*table 2*). The mean number of items affected by psoriasis was 9.4 (95% CI: [8.4-10.3]) out of a total of 32 items. The number of decisions impacted in the five different domains of the MLCDP did not differ significantly between patients with visible psoriasis plaques and those with plaques in non-visible areas (*supplementary figure 1*).

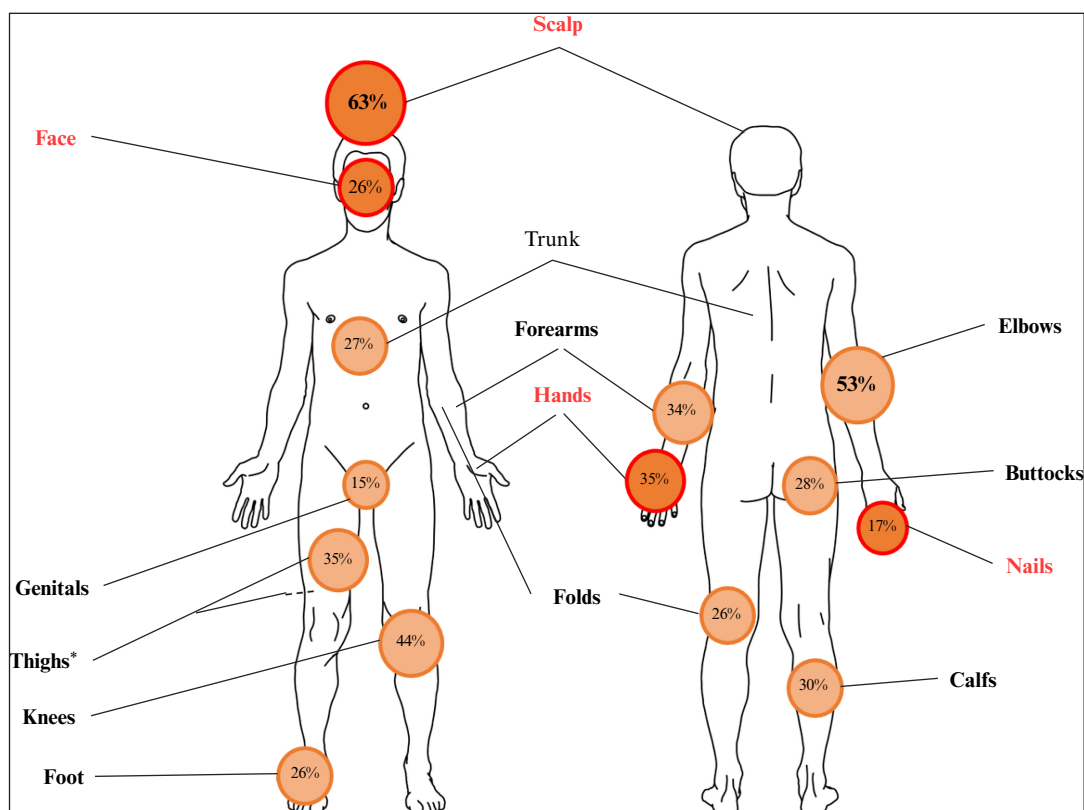


Figure 1. Distribution of psoriatic lesions.

Data are presented as the number of participants (%) reporting lesions in the indicated areas out of a total study population of 301 patients; visible areas are marked in red. Multiple sites could be reported by each participant and a total of 1,434 sites were in fact reported. *Psoriasis on the thighs could be present on the front or back.

Quality of life

Overall, 60.7% ($n = 183$) of participants had a DLQI global score ≥ 6 (moderate impact or greater) and 34.5% ($n = 104$) a score ≥ 11 (large or extreme impact). The median DLQI score was 7 (IQR: 3-13). More detailed information on the score breakdown is provided in *supplementary table 2*. With regard to the individual DLQI items (*figure 2*), skin symptoms (Q1) (87.4% of patients), feeling of embarrassment (Q2) (75.8%) and choice of clothing (Q4) (64.4%) were the items for which an impact was most frequently reported.

The median DLQI score was higher ($p = 0.005$) in patients with visible plaques (median: 8 [IQR: 4-14]; $n = 233$) than in patients with no visible plaques (median: 5 [IQR: 2-8]; $n = 68$).

Study-specific questions on activities of daily living and treatment satisfaction

Activities of daily living impacted by psoriasis

With respect to the specific questions on activities of daily living developed for the study, the proportions of patients reporting an impact of psoriasis on each activity are presented in *figure 3*. More than half of participants declared to have their social life, physical activities and marital relationships impacted by their psoriasis.

Satisfaction with current care

With respect to satisfaction with their current care, 66 participants (21.9%) declared that they were very satisfied, 107 (35.5%) were satisfied, and 64 (21.3%) were quite satisfied. On the other hand, 33 (11.0%) declared that they were quite unsatisfied, 20 (6.6%) were unsatisfied, and 11 (3.7%) very unsatisfied.

Stigma

With regard to stigma, more than half of the participants had suffered a great deal or quite a lot as a result of being considered to have a contagious disease, being unhygienic and being undesirable. In addition, 49.5% reported having suffered from a feeling of isolation since the appearance of the first symptoms of the disease (*table 3*). The proportion of patients reporting that they suffered a great deal or quite a lot did not differ significantly (χ^2 test) between patients with visible plaques and those without, for any of the six stigma items (data not shown).

Psychological well-being and addictive behaviour

Overall, 34.6% of participants scored ≥ 11 on the HADS anxiety subscale, consistent with clinically relevant symptoms and 10.6% scored ≥ 11 on the HADS depression subscale (*table 4*). In addition, 27.6% (83 patients) declared taking psychotropic medicines and 18.3% (55 patients) had undergone psychotherapy. In addition, an increase

Table 2. Impact of psoriasis on major decisions (MLCDP scale).

		Impact on decisions <i>n</i> %	
DOMAIN A: EDUCATION			
	At least one item	68	22.6%
1.	I decided to leave education early	44	14.6%
2.	I decided to change my study subject	56	18.6%
3.	I decided to study near home	46	15.3%
DOMAIN B: JOB/CAREER*			
	At least one item	152	50.5%
1.	I decided to change my job/career	86	28.6%
2.	I decided to give up my job/career	68	22.6%
3.	I decided to take early retirement	44	14.6%
4.	I decided to work flexible working hours	87	28.9%
5.	I decided to select a job/career suitable for my health	105	34.9%
6.	I decided not to take promotion	57	18.9%
7.	I decided to work shorter hours	82	27.2%
8.	I decided to become self-employed	48	15.9%
9.	I decided to remain unemployed	50	16.6%
DOMAIN C: FAMILY/RELATIONSHIPS			
	At least one item	124	41.2%
1.	I decided to change my plans for when to have children	66	21.9%
2.	I decided not to have children	44	14.6%
3.	I decided not to have a sexual relationship	94	31.2%
4.	I decided not to marry or have a long-term partner	57	18.9%
5.	I decided to get divorced or separate from my partner	38	12.6%
DOMAIN D: SOCIAL			
	At least one item	258	85.7%
1.	I decided to change my eating habits	190	63.1%
2.	I decided to change my smoking/drinking alcohol habits	138	45.8%
3.	I decided not to travel or go on holidays abroad	89	29.6%
4.	I decided to move out	50	16.6%
5.	I decided not to move out	48	15.9%
6.	I decided not to move abroad	49	16.3%
7.	I decided to wear different types/colour of clothes/shoes	197	65.4%
8.	I decided not to be involved in community activities	140	46.5%
9.	I decided not to socialise	104	34.6%
10.	I decided not to wear make up	108	35.9%
DOMAIN E: PHYSICAL			
	At least one item	226	75.1%
1.	I decided not to go swimming	179	59.5%
2.	I decided not to take part in any sports activities	132	43.9%
3.	I decided to change to different sporting activities	164	54.5%
4.	I decided to be more physically active	128	42.5%
5.	I decided to give up driving	37	12.3%
<i>The individual 'any influence' items scored by >25% of the sample are highlighted in bold</i>			

in addictive behaviour due to their psoriasis was reported by 66 participants (21.9%) for eating disorders, by 65 participants (21.6%) for tobacco use and by 49 (16.3%) for alcohol consumption. With regard to the CAGE questionnaire, 57 participants (18.9%) scored ≥ 2 , consistent with a high probability of alcoholism (*table 4*).

Personality traits

When participants rated themselves on the combative – resigned and optimist – pessimist dimensions, the mean score was towards the ‘combative’ end of the first dimension (3.3 [95% CI: 3.0 - 3.6]) and towards the ‘optimistic’ end of the second (3.8 [95% CI: 3.5-4.1]).

The median global score for the BRIEF-COPE was 56 (IQR: 48-66), and the median subscores for the approach and avoidance dimensions were 28 (IQR: 22-35) and 22 (IQR: 18-27), respectively, with both scores demonstrating a significant difference ($p < 0.001$; Wilcoxon test). The score distributions for the global score and the two-dimension subscores are presented in *figure 4*.

Associations between Major Life-Changing Decisions Profile score and other variables

The correlation coefficient for the association between the number of stigmatising situations and the total number of MLCDP items for which some impact of psoriasis

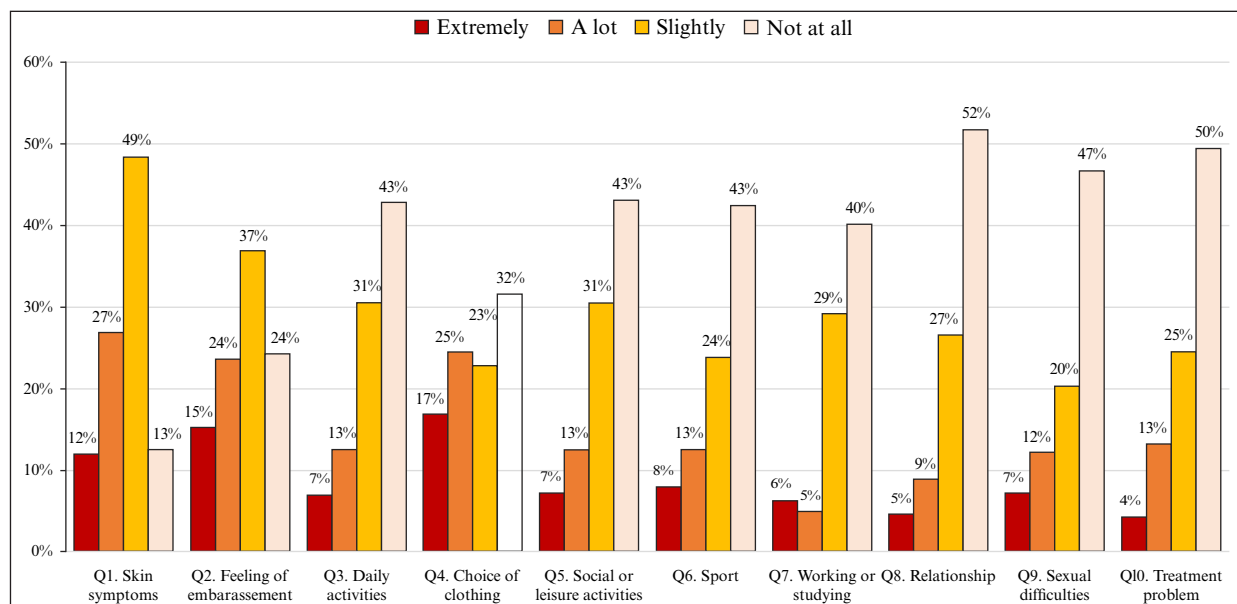


Figure 2. Dermatology Life Quality Index (DLQI) item scores.

The data represent the proportion of subjects affected by their skin condition over the previous seven days out of a total study population of 301 patients.

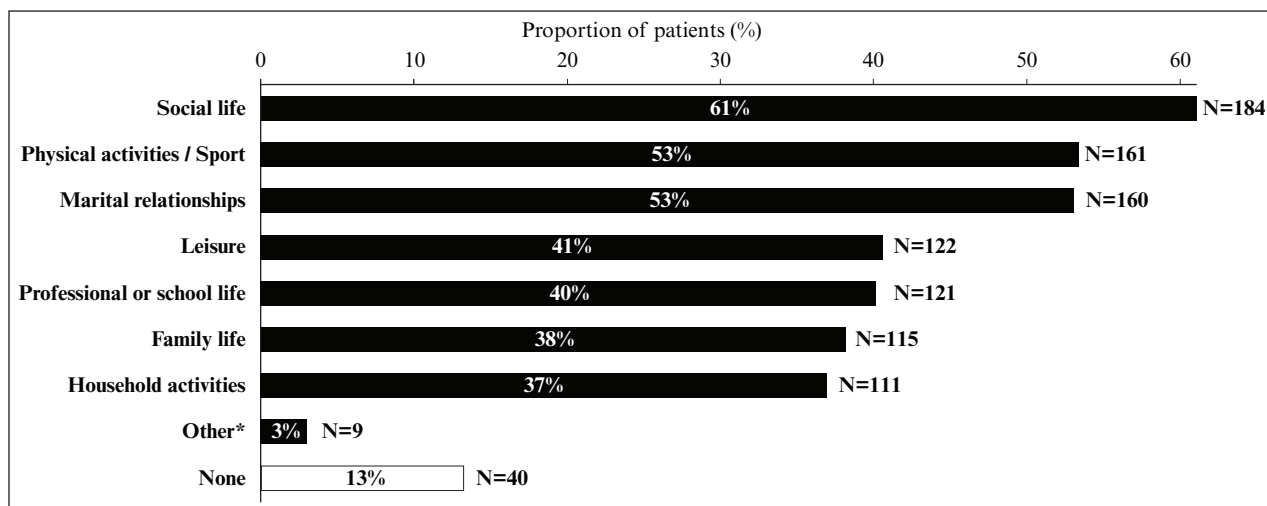


Figure 3. Aspects of daily life impacted by psoriasis.

The data represent the proportion of subjects reporting an impact on different aspects of daily life out of a total study population of 301 patients.

*Social exclusion and relationships (2), hygiene (1), optimism (1), peoples' views and clothes rubbing against plaques (1), physical aspect (1), routine (1), tiredness (1), wearing short sleeves and shorts in public (1).

(item score ≥ 1) was reported was 0.53, and the greater the number of situations, the more participants made life-changing decisions as a result of their disease. In addition, a similar correlation was also noted between the number of impacted MLCDP items and the avoidance dimension of the BRIEF-COPE ($r = 0.59$); in contrast, a correlation was less evident with the approach dimension ($r = 0.25$). Participants with an impacted quality of life (DLQI score > 1) were more at risk (OR: 3.11 [95% CI: 1.49-6.82]) than participants with no impact of having ≥ 5 items with an MLCDP score ≥ 1 . In addition, specifically with respect to the job/career subscale of the MLCDP sub-scores, men reported more impact of their psoriasis than women (mean: 2.5 items

scored ≥ 1 vs. 1.7 items; $p = 0.029$, Wilcoxon test). No such differences according to gender were observed for the other MLCDP subscales.

Discussion

The ROCQ study is the first study to investigate major life-changing decisions specifically in patients with psoriasis. For certain items evaluated in the MLCDP, notably in the social and physical activities domains, psoriasis did lead to changes in lifestyle in between 30% and 70% of participants. These items frequently related to

Table 3. Stigma and feeling of isolation.

	Since the onset of your psoriasis symptoms, how much have you suffered from the following?			
	A great deal	Quite a lot	Not much	Not at all
Type of stigma				
Contagious	73 (24.3%)	109 (36.2 %)	66 (21.9 %)	53 (17.6 %)
Isolated	28 (9.3 %)	67 (22.3 %)	82 (27.2 %)	124 (41.2 %)
Lack of hygiene	53 (17.6 %)	110 (36.5 %)	73 (24.3 %)	65 (21.6 %)
Professional problem (<i>n</i> = 202)	11 (3.7 %)	47 (15.6 %)	52 (17.3 %)	92 (30.6 %)
Ridiculed/insulted	29 (9.6 %)	74 (24.6 %)	80 (26.6 %)	118 (39.2 %)
Undesirable	46 (15.3 %)	121 (40.2 %)	72 (23.9 %)	62 (20.6 %)
Feelings of isolation	40 (13.3 %)	109 (36.2 %)	97 (32.2 %)	55 (18.3 %)

The data represent the proportion of subjects reporting stigma or feelings of isolation of a total study population of 301 patients.

Table 4. Impact of psoriasis on psychological status.

<i>n</i> = 301		
HADS		
	Anxiety dimension	Depression dimension
Mean score [95% CI]	9.6 [9.1 – 10.2]	6.5 [6.0 – 7.0]
Median score [IQR]	9 [6 – 13]	6 [3 – 9]
Score <8 (minimal symptoms)	102 (33.9%)	188 (62.5%)
Score 8-10 (borderline test)	95 (31.6%)	81 (26.9%)
Score 11-21 (clinically relevant symptoms)	104 (34.6%)	32 (10.6%)
Addictive behaviours		
	Increase due to psoriasis - <i>n</i> (%)	
Eating disorders	66 (21.9%)	
Tobacco	65 (21.6%)	
Alcohol	49 (16.3%)	
Gambling	15 (5.0%)	
Illicit drug use	23 (7.6%)	
CAGE/DETA		
Mean score [95% CI]	0.7 [0.6 – 0.9]	
Median score [IQR]	0 [0 – 1]	
Score = 0	196 (65.1%)	
Score = 1	38 (12.6%)	
Score = 2	28 (9.3%)	
Score = 3	25 (8.3%)	
Score = 4	14 (4.7%)	
<i>Data is presented as n (%) unless otherwise specified.</i>		

situations in which individuals would avoid exposing their lesions, such as no longer going swimming, giving up sports activities, deciding to dress differently or refraining from sexual relationships. However, many participants also reported changing their diet or their alcohol consumption after diagnosis and doing more physical activity, which may suggest a belief that healthier living may help improve their psoriasis and that they are not resigned to the situation and are prepared to do something to improve it. The MLCD was developed through interviews with patients with a range of chronic diseases (including a

small number of patients with psoriasis) [15]. However, studies using this questionnaire in patients with psoriasis or other chronic skin diseases have never, to the best of our knowledge, been published. However, a recent systematic review [26] of potential risk factors for CLCI in patients with psoriasis and other chronic skin diseases reported that sociodemographic characteristics (for example, age, gender or education) or clinical features (for example, disease severity, comorbidities or disease duration) were associated with impact. This review also noted the paucity of studies addressing psychological risk factors, such as coping strategies or resilience and

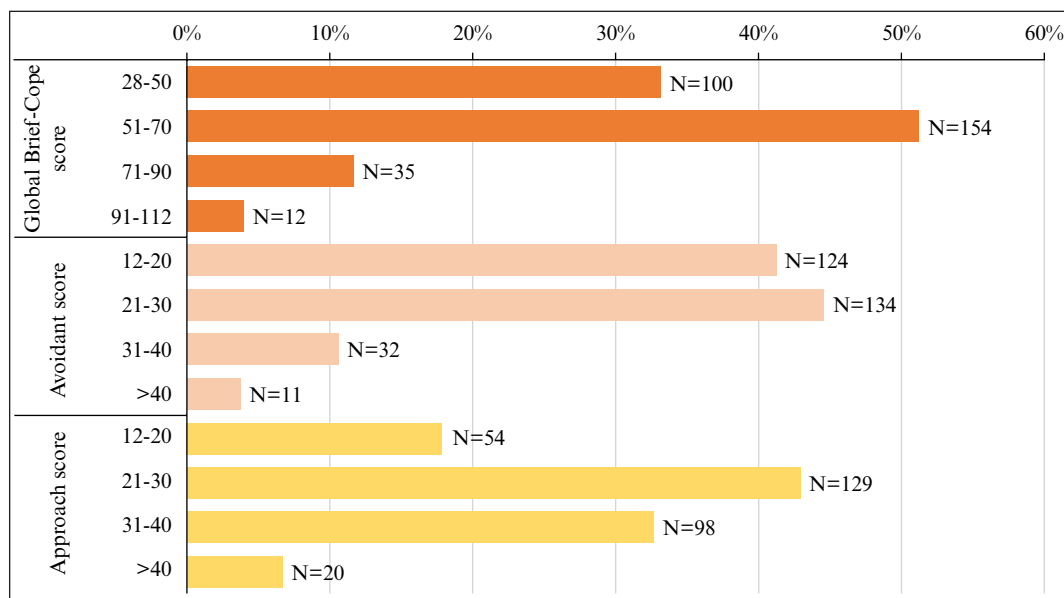


Figure 4. BRIEF-COPE: global score and subscores.

The data represent the proportion of subjects in each score category out of a total study population of 301 patients.

their relationship with CLCI in patients with chronic skin diseases. A survey of the literature concerning patients with alopecia areata revealed that stigma, psychological comorbidity, social or financial impact of disease, and inappropriate coping strategies, which are all important drivers of CLCI, were frequently reported by these patients [10]. In the present study, we also observed that stigma and impaired quality of life were associated with CLCI, defined by a higher MLCDP score.

Consistent with many previous studies [27, 28], we observed impaired quality of life in patients with psoriasis, with over half of participants having a DLQI score ≥ 6 , consistent with at least moderate impact, and over one quarter having a score ≥ 11 (large or extreme impact). We also investigated the occurrence of depressive and anxiety symptoms in participants using the HADS. The mean HADS scores for study participants in the present study were around two-fold higher than reference values for the French general population [29] for both anxiety and depression. We found that 34.6% of participants presented with clinically relevant anxiety symptoms and 10.6% with clinically relevant depression symptoms. These proportions are similar to those reported in a recent study of patients with psoriasis from Brazil which also used the HADS [30]. The relatively high proportion of patients using psychotropic medication or undergoing psychotherapy is also consistent with a high psychological burden in patients with psoriasis.

In spite of the impact of psoriasis on quality of life and social functioning, as well as the CLCI, the study participants considered themselves optimistic and combative, and positive (approach) coping strategies were favoured over negative (avoidance) ones. In addition, participants were in general satisfied with their care, with only one in ten reporting that they were unsatisfied.

The study highlights the need to evaluate systematically the psychological burden in patients with psoriasis by ensuring that there is enough time during consultations to talk about anxiety, stress and stigma, to offer appropriate psychological support when necessary, and to ensure that medical treatment for psoriasis is adapted and adequate. This needs to be done as soon as possible following diagnosis.

The strengths of the study include the relatively large sample size and the large number of PROMs used which has allowed multiple aspects of the impact of psoriasis on participants' lives to be assessed. The multiplicity of these instruments also enabled some cross-validation of the information collected. For example, the life domains impacted by psoriasis documented using the MLCDP are consistent with those identified from direct questioning, and the proportion of patients who reported having increased their alcohol consumption due to their psoriasis was similar to the proportion identified as having a potential alcohol abuse problem based on the CAGE. The principal limitation concerns the representativeness of the sample, who were drawn from a patient online community and chose to participate in the study. Therefore, older adults, patients who were unfamiliar with social media in general and discussion forums in particular, and patients who were not part of the patient community did not participate. The participants may thus have been more concerned about their psoriasis and had higher expectations for care and coped with their disease differently, compared to those with psoriasis who are not actively involved in patient forums. In addition, they may have been more socially involved and thus may have paid more attention to their occupation, economic factors, and the impact of psoriasis on quality of life, which may have biased the results. The data was collected directly from the patient and may not be fully

clinically accurate. Furthermore, participants, who on average had psoriasis for 20 years, were asked to report on the lifetime impact of their psoriasis, and this may have led to some recall bias.

In conclusion, psoriasis carries a high psychological burden and has a strong long-term impact on social functioning. Psychological support should be offered to patients diagnosed with psoriasis early in the disease course in order to help them cope with their disease and limit the negative long-term impact on their lives. In addition, early management with effective treatments to achieve lasting disease control may help attenuate the psychological burden of this chronic disease. ■

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Conflicts of interest: NQT has received honoraria as consultant or speaker from Abbvie, Ammirall, Amgen, Biogen, Janssen, Léo Pharma, Lilly, Novartis, Sanofi and UCB Pharma SA. AG, AC and MH are full-time employees of UCB Pharma SA. EP and A Vives are employees of Carenity, a company that has received sponsorship from UCB Pharma SA to conduct the study; A Villani has received honoraria as consultant or speaker from Abbvie, Ammirall, Janssen, Leo Pharma, Lilly, MSD, Novartis and UCB Pharma SA.

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