

ORIGINAL ARTICLE

Quality of life and stigmatization in people with skin diseases in Europe: A large survey from the 'burden of skin diseases' EADV project

Paolo Gisondi¹  | Luis Puig²  | Marie Aleth Richard³  | Carle Paul⁴ |
 Tamar Nijsten⁵ | Charles Taieb⁶  | Alex Stratigos⁷ | Myrto Trakatelli⁸ |
 Carmen Salavastru⁹ | for the EADV Burden of Skin Diseases Project Team

¹Section of Dermatology and Venereology, Department of Medicine, University of Verona, Verona, Italy

²Department of Dermatology, Hospital de la Santa Creu i Sant Pau, Universitat Autònoma de Barcelona, Barcelona, Spain

³CEReSS-EA 3279, Research Centre in Health Services and Quality of Life Aix Marseille University, Dermatology Department, University Hospital Timone, Assistance Publique Hôpitaux de Marseille, APHM, Marseille, France

⁴INSERM Infinity U1291, Université de Toulouse et CHU, Toulouse, France

⁵Department of Dermatology, Erasmus MC, Rotterdam, The Netherlands

⁶Patients Priority, EMMA, Fontenay Sous-Bois, France

⁷Department of Dermatology, Andreas Syggros Hospital, Medical School, National and Kapodistrian University of Athens, Athens, Greece

⁸Second Department of Dermatology and Venereology of Aristotle School of Medicine Papageorgiou Hospital, Thessaloniki, Greece

⁹Department of Pediatric Dermatology, Carol Davila University of Medicine and Pharmacy, Colentina Clinical Hospital, Bucharest, Romania

Correspondence

Marie Aleth Richard, Dermatology Department CHU Timone, 264 rue saint Pierre 13005 Marseille, France.
 Email: mariealeth.richard@ap-hm.fr

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Paolo Gisondi, Luis Puig, Marie Aleth Richard, Alex Stratigos, Myrto Trakatelli, Carmen Salavastru contributed equally to this article.

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Abstract

Background: Several large studies on the burden of skin diseases have been performed in patients recruited in hospitals or clinical centres, thus missing people with skin diseases who do not undergo a clinical consultation.

Objectives: To evaluate the burden of the most common dermatological diseases in adult patients across Europe, in terms of quality of life, work life, and stigmatization.

Methods: Population-based survey on a representative sample of the European general population aged 18 years or older. Participants who declared to have had one or more skin problem or disease during the previous 12 months completed the Dermatology Life Quality Index questionnaire, and answered questions regarding the impact of their skin disease on daily and work life, anxiety/depression, and stigmatization.

Results: The study population included 19,915 individuals, 44.7% of whom were men. Quality of life was particularly impaired in people with hidradenitis suppurativa (HS), and sexually transmitted diseases. About a half of participants with acne, alopecia, or chronic urticaria, and about 40% of those with atopic dermatitis (AD), skin cancers, or psoriasis reported a modest to extremely large effect of the disease on their quality of life. Overall, 88.1% of participants considered their skin disease as embarrassing in personal life and 83% in work life. About half of the respondents reported sleeping difficulty, feeling tired, and impact of the disease on taking care of themselves. Concerning stigmatization, 14.5% felt to have been rejected by others because of the skin disease, and 19.2% to have been looked at with disgust. Anxiety and depression were frequently reported by patients with all the diseases.

Conclusions: Skin diseases may heavily affect patients' daily and work life, and cause feelings of stigmatization. An early intervention is needed to avoid consequences on the patients' life course.

INTRODUCTION

Several skin diseases are known to significantly affect patients' quality of life.¹ Not only life-threatening diseases, such as malignant melanoma, but also chronic diseases, such as psoriasis and atopic dermatitis, may severely impair social and personal daily life, and have psychological consequences, such as depression and anxiety.² The British All Party Parliamentary Group on skin (APPGS)³ stated that key quality of life domains for people with skin diseases include: 'symptoms and diagnosis; treatment; self-esteem and psychological health; life-changing decisions and work; social, sexual and leisure activities; physical functioning; family relationships; sleep disturbance and schooling; ethnic and cultural issues; and environmental issues.' A number of these aspects are not only concomitant with the diseases, but may also have a long-term effect influencing life decisions,⁴ for example in work life.⁵⁻⁷ Patients with chronic skin diseases in particular may be often absent from work because of physical disability (absenteeism), or even if they are able to work, their productivity may be decreased (presenteeism). Also, patients with visible lesions may experience stigmatization,^{8,9} which may be described as experiences of social disapproval, discrediting or devaluation based on an attribute or physical mark.¹⁰

Several large studies on different aspects of the burden of skin diseases have been performed;² however, the study population was very often constituted by patients recruited in hospitals or clinical centres, thus missing persons with skin diseases who do not undergo a clinical consultation.

The aim of the present study was to evaluate the burden of the most common dermatological diseases of adult patients across Europe, in terms of impact on quality of life, work life, and stigmatization.

MATERIALS AND METHODS

Study population

This multinational, cross-sectional study was conducted in the framework of the EADV population-based survey on the 'Burden of skin diseases in Europe'. Methods have been previously described in detail.¹¹ In brief, data were collected using a web-based online survey on a representative sample of the general populations aged 18 years or more of 27 European countries (24 belonging to the European Union plus United Kingdom (UK), Switzerland (SW) and Norway (NO)). Proportional quota sampling with replacement design was used for each country based on the distribution of the population according to age, sex, administrative region, environment, and income. The survey was conducted from November 10, 2020 to August 5, 2021. As the study used anonymized data and did not involve any clinical examination, institutional review board approvals were not required. Based on the results from previous studies,^{12,13} the sample size for each country was estimated as 1000 to

4000 individuals. Only three European countries could not be included, that is, Cyprus, Luxembourg, and Malta, that represent only 0.3% of the total population.

Questionnaire and outcomes

Participants who reported at least one skin disease or skin problem during the previous 12 months were included in the present study. Mole check and skin cancer screening were excluded. Also, people reporting an unpleasant sensation related to the skin in the absence of a skin disease were not included. If participants reported more than one skin disease, it was asked to answer the questionnaire referring to the most bothering one. Dermatology-related quality of life was assessed using the Dermatology Life Quality Index (DLQI),¹⁴ constituted by 10 items with possible answers on a four-point scale from 'never' to 'all the time'. Higher scores indicate a worse quality of life. The total score has been categorized by Hongbo et al.¹⁵: 0-1 no effect at all on patient's life; 2-5 small effect on patient's life; 6-10 moderate effect on patient's life; 11-20 very large effect on patient's life; 21-30 extremely large effect on patient's life. The presence of anxiety or depression was evaluated by a question with possible answers 'no', 'moderately', 'extremely'. Participants were asked to answer specific questions about daily life, stigmatization, and how much their work or personal life were affected and impaired by the skin disease. The impact of the disease on personal and work life was evaluated on a 4-point scale from 'not embarrassing' to 'very embarrassing'. Questions on daily life concerned sleeping difficulty, feeling tired, impact on time to take care of themselves and their family. Moreover, it was asked if the impact on personal life was high (disrupting life), moderate (the patient can control it), mild, or none. Specific information on professional life concerned adapting working hours, reorienting professional activity, refusing a professional offer, not getting the job hoped to, choosing work with the skin problem in mind. Stigmatization was evaluated by three questions concerning the feeling of being rejected by others, of being looked at with disgust, and to have been refused to access leisure facilities.

Statistical analysis

Qualitative and ordinal variables were described by their number and frequency. Median and Interquartile Range (IQR), as well as mean and standard deviation (SD), were used to describe DLQI scores. In each country, the total population of individuals suffering from each skin problem or disease was calculated by direct extrapolation of the proportions from the proportionally stratified sample.

The statistical analyses were carried out using the HARMONIE 1.7 software, registered with the INPI under the name DSE-HARMONIE since 25 April 2013 with the registration number 4000937.

RESULTS

The survey was conducted on a total of 44,689 individuals, 21,887 (49.0%) men and 22,802 (51.0%) women, out of 408,436,455 inhabitants aged 18 or more of the 27 included European countries. Of them, 22,986 (50.9%) participants declared having had at least one skin disease, or unpleasant sensation related to the skin during the previous 12 months. Excluding participants who reported only a skin-related unpleasant sensation with no skin disease, as well as mole check and cancer screening, 19,915 individuals (43.3%) reported a skin disease. This is the population that we analysed in the present study. At the question of whether the skin condition

or disease was bothering, 15,401 (34.4%) participants gave a positive answer. Characteristics of the 19,915 individuals with skin diseases are described in [Table 1](#).

[Figure 1](#) represents the distribution of the DLQI scores in categories in participants with the main skin diseases. Quality of life was extremely or very much impaired in the majority of people with hidradenitis suppurativa, and in a half of those with STD. About a half of participants with acne, alopecia, or chronic urticaria, and about 40% of those with atopic dermatitis, skin cancers, or psoriasis reported a modest to extremely large effect of the disease on their quality of life.

In the group of participants who reported a skin disease ($n = 19,915$), 35.4% had one skin disease, 24.3% two, 14.1%

TABLE 1 Description of sociodemographic and clinical characteristics of 19,915 individuals who reported a skin disease.

Variable	Level	<i>n</i>	%	95% margin of error
Sex	Male	8827	44.7	0.69
	Female	11,088	55.3	0.69
Age (years)	18–24	2318	12.0	0.45
	25–34	3823	19.1	0.55
	35–44	3746	18.5	0.54
	45–54	3749	18.9	0.54
	55–64	3289	16.1	0.51
	65+	2990	15.4	0.50
Living area	Urban area of a big city	5482	28.0	0.62
	Suburban area outside a big city or in a medium-sized city	6171	31.9	0.65
	Rural area or small town	8262	40.1	0.68
Comorbidities	Bone and joint diseases	4781	22.7	0.58
	Cardiovascular diseases	2549	11.9	0.45
	Diabetes or endocrine or metabolic diseases	2284	11.6	0.44
	Gastrointestinal disorders	4749	24.5	0.60
	Neurological diseases	1591	7.6	0.37
	Psychiatric disorders	1226	6.2	0.34
	Psychological problems (anxiety, depression)	4551	22.6	0.58
	Respiratory diseases	3200	16.1	0.51
	Urinary and genital diseases	5694	28.9	0.63
Main skin diseases	Fungal skin infection	4053	20.6	0.56
	Acne	2452	12.4	0.46
	Atopic dermatitis, eczema	2385	12.6	0.46
	Alopecia (or hair loss)	2331	11.8	0.45
	Psoriasis	1758	9.0	0.40
	Sexually transmitted diseases	1258	6.4	0.34
	Rosacea	865	4.6	0.29
	Chronic urticaria	468	2.3	0.21
	Non melanoma skin cancers	462	2.6	0.22
	Vitiligo	355	1.8	0.19
	Hidradenitis suppurativa	280	1.4	0.17
	Melanoma	255	1.4	0.16

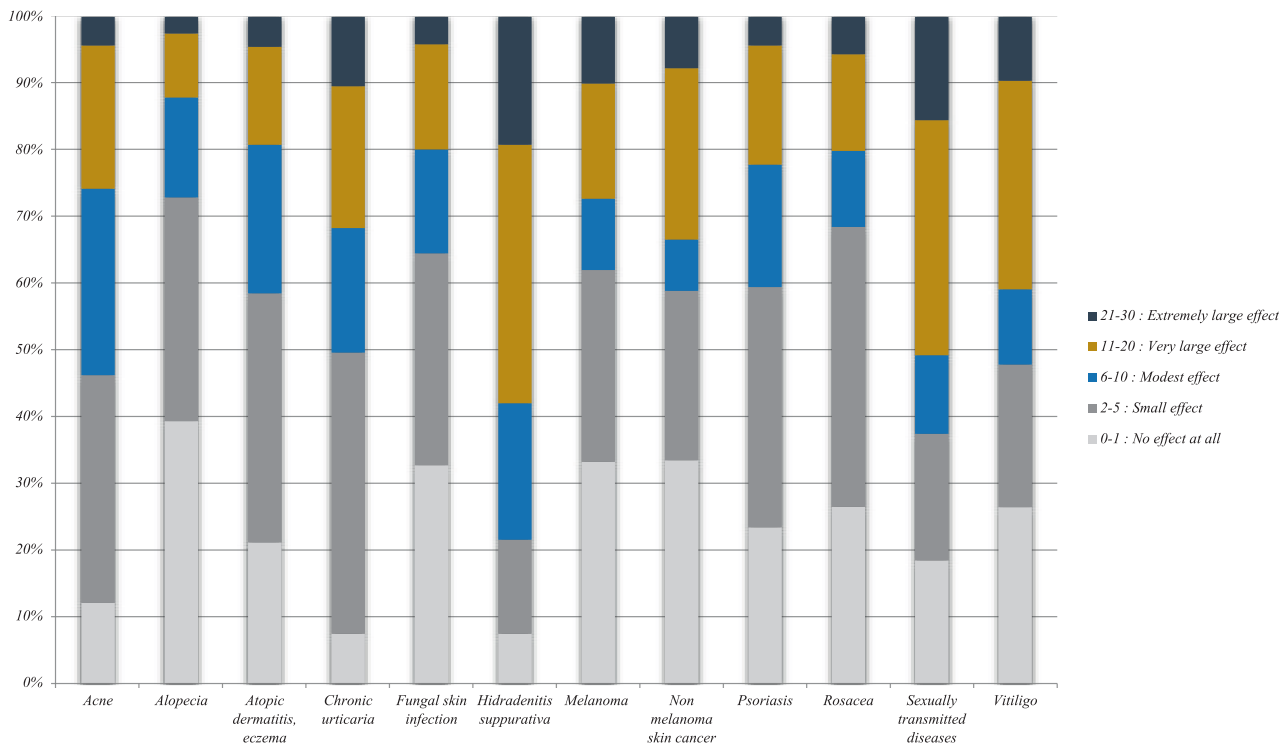


FIGURE 1 Percentage of patients in each category of the Dermatology Life Quality Index (DLQI) in the 12 most frequent skin diseases.

three, and 26.3% had four skin diseases or more. On average, they reported 3.0 ± 3.2 skin diseases [median 2.0]. The DLQI median (IQR) score was strongly associated with the number of skin diseases from 1.0 (4.0) when only a skin problem was present, 2.0 (5.0) for two problems, 3.0 (8.0) for three, and 8.0 (15.0) for four skin problems or more. The respective DLQI mean (SD) values were 3.4 (4.8), 4.0 (5.2), 5.4 (5.8), and 9.7 (8.1). Table 2 summarizes the distribution of the answers to the questions on daily life, stigmatization, personal and work life. About half of the respondents reported sleeping difficulty, feeling tired, and impact of the disease on taking care of themselves. Concerning stigmatization, 14.5% felt to have been rejected by others because of the skin disease, 19.2% to have been looked at with disgust, and 10.8% answered that access to leisure facilities had been refused. And 14.9% of participants reported a high impact of their skin disease on their life, and almost half of them reported a specific problem in their work life. As shown in Figure 2, 88.1% of participants considered their condition to be embarrassing in personal life and 83% in work life.

Looking at specific diseases (Figure 3), patients with hidradenitis suppurativa had high rates of personal (67.3%) and professional impact (63.7%), stigmatization (35% and 37% for rejection and disgust, respectively), and anxiety/depression (63.4%). Work life was particularly impaired in patients with acne (47.5%) or urticaria (59.7%). Sleep disturbance (62.2%) and tiredness (73.4%) were most frequently reported by patients with chronic urticaria. Acne was most frequently associated with time requirements to take care of the disease (65.7%). Side effects of treatment were reported to be especially burdensome in patients with acne (50.9%) and

urticaria (53.9%). Stigmatization, and in particular feelings of disgust, was reported by a high percentage of persons with acne (38.2%) or vitiligo (40.4%). Anxiety and depression were frequently reported by patients with all the conditions.

DISCUSSION

In this study on a representative sample of the general population of 27 European countries, we observed a high impact of several skin diseases on the life of affected people. Overall, about half of participants with at least one skin disease found that their condition was quite or very embarrassing in their personal and work life. Half of them reported moderate or high anxiety or depression, and between 15% and 20% of persons with skin diseases reported feelings of stigmatization. The significant impact of many skin diseases on patients' quality of life is well known.^{16,17} An important component of health and wellbeing is sleep. A low quality of sleep may also increase the risk of some diseases, such as cardiovascular ones.¹⁸ In our study, we observed that a high proportion of participants with skin diseases reported sleep disturbance, in particular those with hidradenitis suppurativa, chronic urticaria, and atopic dermatitis, followed by acne and vitiligo. In a French study,¹⁹ sleep disorders were present in 30%–50% of patients with acne, rosacea, eczema, psoriasis or urticaria. Insomnia and poor sleep are frequently associated with itch and nocturnal pruritus,²⁰ and thus they are present in patients with psoriasis,²¹ chronic urticaria, and atopic dermatitis.²² In the study by Jensen et al.²¹ 25% of patients with psoriasis reported clinical insomnia, and 53.6%

TABLE 2 Prevalence of problems in personal, work, and daily life, and stigmatization.

Variable	Level	N ^a	%	95% margin of error
Personal life	High impact, disrupting life	3480	17.1	0.52
	Moderate impact (I can control it)	6417	32.1	0.65
	Mild impact	3317	16.5	0.52
	No influence	608	3.1	0.24
	I have no bothering skin problems	6093	31.2	0.64
Work life	Adapt working hours	981	21.2	1.19
	Reoriented professional activity	1067	23.4	1.23
	Refused a professional offer	763	17.2	1.09
	Did not get the job hoped to	585	12.9	0.97
	Chose my work with skin problem in mind	793	16.7	1.08
	Any of that	2089	45.7	1.44
		N ^b	%	95% margin of error
Daily life				
Sleeping difficulty	Very much	899	6.9	0.42
	A lot	1776	13.3	0.57
	A little	3872	28.4	0.76
	Not at all	7145	51.4	0.84
Feel tired	Very much	1043	7.8	0.45
	A lot	2164	16.0	0.61
	A little	3992	28.3	0.75
	Not at all	6493	48.0	0.84
Impact on time to take care of her/himself	Very much	966	7.3	0.44
	A lot	2151	15.8	0.61
	A little	4223	29.8	0.77
	Not at all	6352	47.0	0.84
Impact on time to take care of her/his family	Very much	593	4.5	0.35
	A lot	1159	8.8	0.47
	A little	2137	15.5	0.61
	Not at all	6405	45.3	0.83
	Not relevant	3398	25.9	0.73
Stigmatization				
Feel left out/rejected by others	Strongly agree	546	4.0	0.33
	Agree	1560	11.6	0.54
	Neutral	2228	16.3	0.62
	Disagree	3665	25.4	0.73
	Strongly disagree	5693	42.8	0.83
Access to leisure facilities refused	Strongly agree	480	3.5	0.31
	Agree	1104	8.1	0.46
	Neutral	1649	11.6	0.54
	Disagree	3564	24.9	0.72
	Strongly disagree	6895	51.9	0.84
Impression to be looked at with disgust	Strongly agree	711	5.3	0.38
	Agree	2031	15.3	0.60
	Neutral	2473	17.7	0.64
	Disagree	3228	22.5	0.70
	Strongly disagree	5249	39.1	0.82

Note: If several skin problems are reported, the answers correspond to the most bothering one.

^aAt least one skin problem N = 19,915.

^bAt least one bothering skin problem or unpleasant sensation N = 13,692.

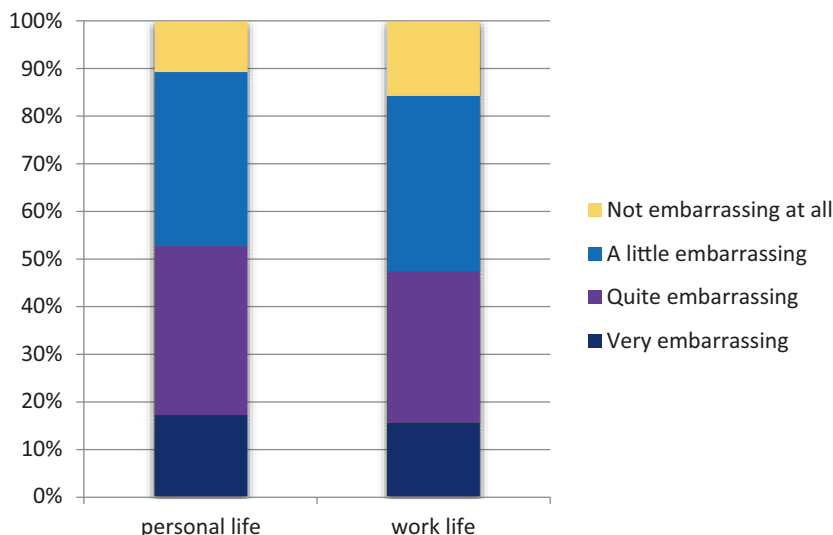


FIGURE 2 Percentage of participants reporting an impact of their skin disease on personal and work life.

were poor sleepers, similarly to what reported in the present study. However, pruritus may not be the only reason for insomnia in dermatological patients. Some studies showed an association between chronic urticaria and obstructive sleep apnea,²³ even though a clear explanation for this link has not been given. A low sleep quality appears to be associated with acne. In a study,²⁴ this link was still present when adjusting for depressive symptoms, suggesting that acne may directly have an impact on quality of life and mental health. Sleep disturbance was observed also in patients with hidradenitis suppurativa²⁵ and rosacea.²⁶

Dermatological diseases may have an impact on work life. Absenteeism or presenteeism can be a direct consequence of the clinical condition, and may also influence the life course of a person. In fact, a number of participants in our study with a skin disease reported that they had to re-orient their professional activity, to refuse a professional offer, or were declined from a job they wanted. This is an example of the so-called Cumulative Life Course Impairment (CLCI),⁴ that is, the long-term effect of a chronic disease on life course. In our study, the impact of the skin diseases on work life was considered very or quite burdensome by approximately 50% of participants, with the highest impact in patients with hidradenitis suppurativa (63.7%). It was particularly high also in acne and chronic urticaria. Work-related problems have been reported in patients with psoriasis,⁷ in particular work limitation due to hand involvement and work days lost to clinical assessment and treatment, but also because of the burden of emotions such as shame and anger. Different studies found increased levels of sick leave in patients with atopic dermatitis,⁶ as well as absenteeism and presenteeism,²⁷ and decreased work productivity.²⁸ In addition, absenteeism was a significant predictor of perceived productivity loss in patients with hidradenitis suppurativa.²⁹ Increased absenteeism, presenteeism, and

work productivity loss was reported also in patients with chronic urticaria,³⁰ while disruption of personal and professional life was noted in adults with acne,³¹ and of work life impairment in patients with rosacea.³¹ In our study, moderate or high levels of anxiety or depression were reported in many participants with skin diseases, with percentages greater than 60% in hidradenitis suppurativa, acne, and chronic urticaria. Several studies have shown that patients with chronic skin diseases have an increased risk of depression and anxiety. In a multicenter European study,² the association with depression and anxiety was higher in patients with psoriasis, atopic dermatitis, hand eczema, and leg ulcers. People with skin diseases may experience stigmatization,³² with consequent discrimination and social rejection. Stigma is frequently experienced by patients with psoriasis,³³ in particular in the components concerning anticipation of rejection and feelings of guilt and shame,⁹ in patients with hidradenitis suppurativa³⁴ and vitiligo.³⁵ Stigma usually depends on the visibility of the condition, but also on the fear of contagiousity, or, as in hidradenitis suppurativa, on the smell of skin lesions. In our study, fear of rejection was reported not only by a high percentage of participants with psoriasis, hidradenitis suppurativa, and vitiligo, but also with acne and alopecia. Stigmatization is a significant contributor to the impairment of quality of life,³⁶ and thus it is an important component of the overall burden of a disease. Our study emphasizes the importance of the impact that many skin diseases, even those considered not clinically severe, may have on patients' life.

The main limitation of this study is that all data were collected through questionnaires. As a consequence, diagnoses were based on self-reporting by participants, and we did not have any information on the severity of the disease. On the other side, this methodology allowed to reach also people who do not undergo regularly a clinical

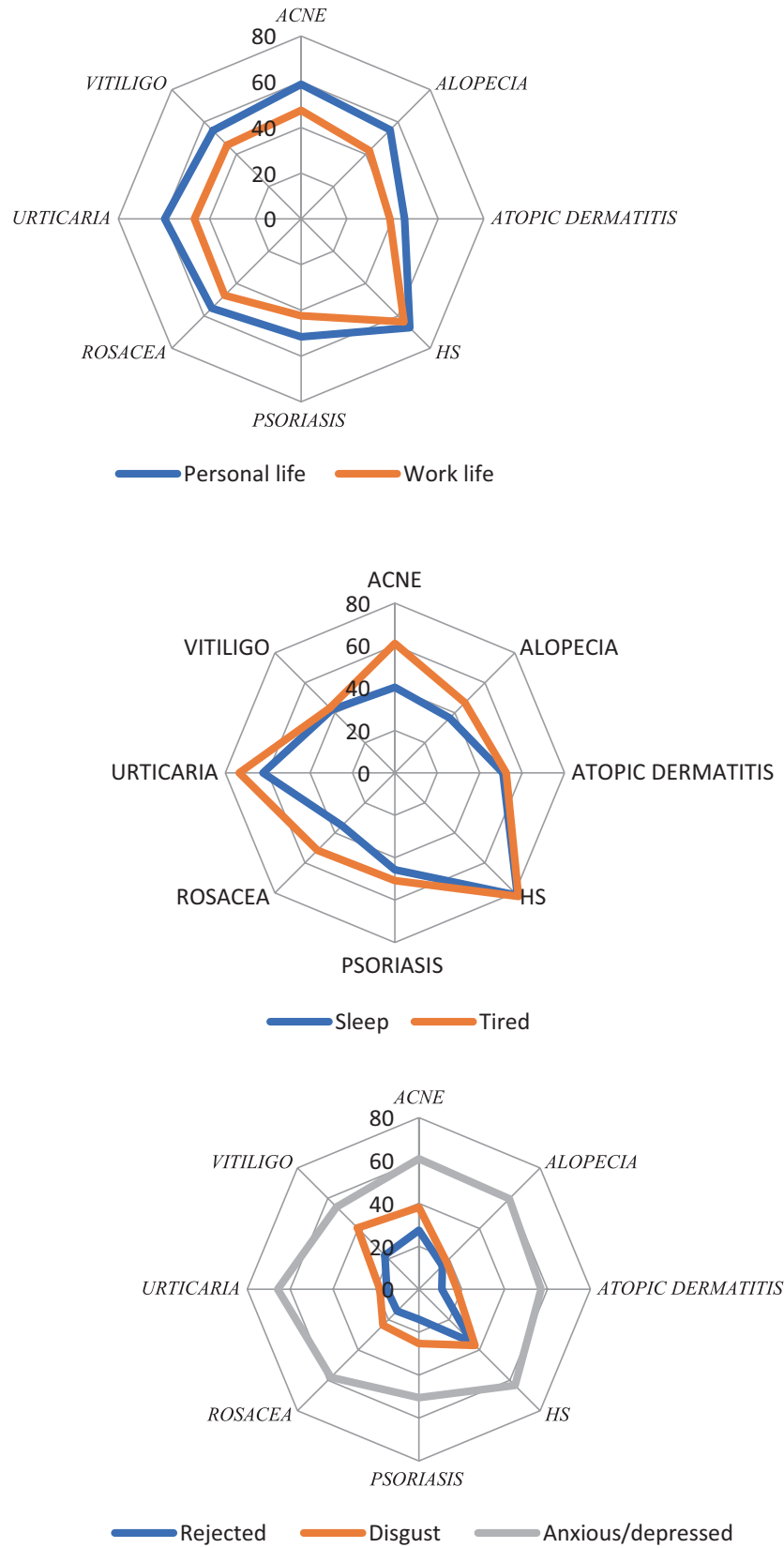


FIGURE 3 Percentage of participants with different skin diseases who reported daily life and work life impact, stigmatization, and anxiety/ depression. Personal life, work life: “very embarrassing”/“quite embarrassing”. Sleep, tired, self-care, family care: “very much”/“a lot”/“a little”. Rejected, disgust: “strongly agree”/“agree”. Anxious/depressed: “extremely”/“moderately”.

consultation, and thus to obtain data from the general population instead that from a selected population of dermatological patients. Another limitation is that, while we used a validated questionnaire to measure quality of life, we used only single questions to evaluate specifically the impact of the skin diseases on work life, daily life, and stigmatization. However, this choice allowed to have a short questionnaire that could be filled quickly by the participants.

In conclusion, our study highlights the psychosocial burden experienced by people with skin diseases, and the need to address their impact on quality of life and stigmatization in the context of patient management. In particular, the impact on work life highlights the need of an early intervention, in order to avoid consequences on the patients' life course.

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

Data can be provided for valid scientific non-commercial purposes.

ORCID

Paolo Gisondi  <https://orcid.org/0000-0002-1777-9001>

Luis Puig  <https://orcid.org/0000-0001-6083-0952>

Marie Aleth Richard  <https://orcid.org/0000-0002-0870-9132>

Charles Taieb  <https://orcid.org/0000-0002-5142-2479>

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