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ORIGINAL ARTICLE

The journey of patients with skin diseases from the first consultation to the diagnosis in a representative sample of the European general population from the EADV burden of skin diseases study

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Abstract

Background: The journey of patients with skin diseases through healthcare has been scarcely investigated.

Objective: To analyse the journey of people with skin diseases in the different healthcare environment in Europe.

Methods: This multinational, cross-sectional, European study was conducted on a representative sample of the adult general population of 27 European countries. The prevalence of the most frequent skin diseases was determined. Information was collected on the patient journey from the first medical consultation to the diagnosis, and the reasons for not consulting a healthcare professional.

Results: On a total of 44,689 individuals, 30.3% reported to have consulted a dermatologist during the previous 2 years. Participants consulted mainly for mole control or skin cancer screening (22.3%), followed by chronic skin diseases (16.2%). The diagnoses of acne, atopic dermatitis, psoriasis and rosacea were made most frequently by a dermatologist, while fungal skin infections were diagnosed more often by a general practitioner (GP), and sexually transmitted diseases (STD) by other specialists. The diagnosis was not always definitive at the first consultation, in particular for STD. The percentage of people who did not consult a healthcare professional for their

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skin disease was particularly high for acne (36.4%), alopecia (44.7%) and fungal infection (30.0%). Moreover, 17.7% of respondents with psoriasis did not consult. A high percentage of participants with alopecia thought that the disease was not worrying, while patients with psoriasis often answered that they were able to manage the disease since they had already consulted a doctor. Many patients with acne (41.1%) and fungal infection (48.2%) thought that they were able to handle the disease by themselves.
Conclusion: The analysis of the self-reported medical journey of patients with common skin diseases may allow to understand the unmet needs of patients, thus improving outcomes and reducing expenses.

INTRODUCTION

Skin diseases are very frequent in the general population. It has been estimated that they affect between 30% and 70% of people worldwide.[1,2] In the EADV burden of skin diseases study on a representative sample of the European general population, which included also data analysed in the present report, 50.9% of participants reported having had at least one skin disease, or skin-related symptom during the previous 12 months.[3] In England and Wales, skin diseases are the most frequent reason for consultation in general practice,[4] and in the Netherlands it is in the top three accounting for 14% of all care provided by GPs (https://www.nivel.nl/sites/default/files/bestanden/Zorglandschap_zorggebruik_in_de_eerste_lijn.pdf) It is reasonable to infer that this is the case also in other European countries. General practitioners (GPs) may diagnose and treat the patient by themselves, however patient referral to a specialist may be necessary due to diagnostic uncertainty.[5] In the Netherlands, in which a referral from the GP is required to visit a specialist as is the case in United Kingdom (UK), dermatology has the highest referral rate of all medical specialties (>30 referrals per 1000 registered GP patients) (https://www.nivel.nl/nl/nivel-zorgregistraties-eerste-lijn/verwijzingen-naar-de-tweede-lijn). This high referral rate demonstrates the high volume of dermatological diseases and the need of specialized care. Also, patients may decide to directly consult a dermatologist. Percentages may greatly differ from one country to another, mainly due to the different healthcare systems. For example, in an Italian survey,[6] 73% of the participants consulted the GP for a skin problem, with only 27% referring directly to the private dermatologist, while in a French study,[7] GP was the first healthcare provider in 54% of those interviewed. Type of consultations (or care demand) in general practice and in dermatology usually differ, since, as observed in the French study,[7] dermatologists are consulted mainly for chronic skin diseases, surgical intervention, and naevi check-up, while for acute skin problems the GP is the first healthcare reference. The first consultation is a pivotal step of the so-called patient journey in the health care system. Since skin diseases are a heterogeneous group of conditions, with different levels of severity and quality of life impairment, it is not possible to trace a single pathway for the patient. However, the first steps may affect the entire journey, and may be the beginning of a long and delayed pathway, as it is the case for hidradenitis suppurativa.[8] The diagnosis may be done by the first consulted healthcare provider, but, depending on the disease, there may be a long diagnostic delay and/or use of suboptimal or inappropriate treatments delaying appropriate disease management and potentially generating undue suffering and unjustified costs. In the framework of the large EADV burden of skin diseases study on a representative sample of the European general population, the aim of the present evaluation was to describe the medical journey of people with skin diseases from the first consultation to the diagnosis.

METHODS

Study population

This multinational, cross-sectional study was conducted in the framework of the EADV population-based study on the 'Burden of skin diseases in Europe'. Methods have been previously described in detail.[3] In brief, from 10 November 2020 to 5 August 2021 a study was conducted on a representative sample of the general population aged 18 years or more of 27 European countries [24 belonging to the European Union (EU) plus UK, Switzerland (SW) and Norway (NO)]. Only three European countries from the EU group, that is, Cyprus, Luxembourg and Malta, could not be included, however they represent only 0.3% of the total population.

Questionnaires and outcomes

The main questions identified participants with at least one skin disease or unpleasant skin-related sensation during the previous 12 months from a given list. Module A of the questionnaire was completed by all interviewees and consisted of information on socio-demographic characteristics, skin phototype, comorbidities, medical consultations in the previous 12 months and general health status/quality of life. Module B was completed only by individuals reporting at least one skin disease or unpleasant skin-related sensation during the previous 12 months. It included clinical data and different measures of the impact of the disease on patients. Moreover, it collected information about the healthcare pathway of the

patient, demand of care and the role of health professionals. Participants were asked about which skin problem was the reason for consultation, who was the first consultation addressed to (dermatologist, GP, allergist or other), who made the diagnosis, where [in a private practice, in a private clinic, in a national health service (NHS) hospital, at the office of a NHS doctor, other], when the diagnosis was confirmed (immediately made and confirmed by the first doctor, completely confirmed after consultation with one or more other doctors, or not fully confirmed), and if other exams were required to make the final diagnosis. The reasons for not consulting a doctor were also questioned.

When more than one skin disease was present, the participants were asked to answer the questions referring to the most bothering condition.

Statistical analysis

Qualitative and ordinal variables were described by their number and frequency. All the analyses were performed on the whole sample, and separately for participants with acne, alopecia (all types), atopic dermatitis, fungal infections, psoriasis, rosacea, skin cancer (both melanoma and non-melanoma) and sexually transmitted diseases (STD). As for skin cancer, only patients who had consulted a clinician have been included, in order to be sure of the diagnosis of cancer.

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 study was conducted on a total of 44,689 individuals, out of 408,436,455 inhabitants aged 18 or more of the 27 European countries included. The sociodemographic and clinical characteristics of participants are reported in Table 1. Participants who declared having had at least one skin disease or skin-related unpleasant sensation during the previous 12 months were 22,986 (50.9%), those who reported at least one disease were 21,401 (47.2%), and 19,915 individuals (43.4%) reported a skin condition or disease excluding mole check and cancer screening. The most common specific diagnosis ranged between 1.5% (skin cancer) and 10% (fungal infection) of participants. Among all participants, 18.4% consulted a dermatologist in the last 12 months, 30.3% in the last 2 years, and half of the participants in the last 5 years (Table 2). Among participants with self-reported acne, 63.6% reported to have seen a healthcare professional (HCP) (i.e. doctor, pharmacist, or nurse) during the previous 12 months. The percentages were 55.3% for alopecia, 78.1% for atopic dermatitis, 70% for fungal infections, 82.1% for psoriasis, 77.1% for rosacea and 88.1% for STD (results not shown). The reasons indicated by the participants for dermatologist consultation varied, but mole check and skin cancer screening including mole check was most frequently reported (Table 3). For several common skin diseases, the dermatologist was most frequently consulted among different health care providers, except for fungal infections and STD (Figure 1). The proportion of clinicians who were first consulted and of those who made the diagnosis were comparable. Between 70% and 90% of the participants indicated that the GP and/or dermatologist diagnosed their disease. In about 30% of cases skin cancer was diagnosed by another specialist, as well as in more than 60% of participants with STD. In this European study, about half the diagnoses were made in a private practice, and around 40% in the National Health System (Figure 2). The proportions of the type of health care setting were similar for the different diseases. Among patients who went to a doctor for their disease, the diagnosis was definitive in the first consultation for one-half to three-quarters of the patients with common skin diseases and reached more than 90% after consultation of additional physicians (Figure 3). In particular, in about 40% of participants the diagnosis of skin cancer or STD was made after consultation of at least another medical specialist. Diagnostic procedures (i.e. biopsy or other examinations) were required to confirm the diagnosis in 33.9% of patients with acne, 40% with alopecia, 31.2% with atopic dermatitis, 28.1% with fungal infection, 32.4% with psoriasis, 23.5% with rosacea, 84.6% with skin cancer and 73.6% with STD. In particular, biopsy was required in 13.7% (acne), 9.8% (alopecia), 12.0% (atopic dermatitis), 10.1 (fungal infection), 13.4% (psoriasis), 9.4% (rosacea), 62.5% (skin cancer) and 41.8% (STD) of participants.

The percentages of participants who did not consult a HCP for their skin disease were particularly high for acne, alopecia and fungal infection (Table 4). Furthermore, 21.9% of patients with atopic dermatitis, 17.7% of patients with psoriasis and 11.9% with STD did not consult a HCP. The main reasons for not consulting a HCP were that participants felt they could handle the disease on their own or with their family (i.e. self management), that it was not worrying enough to consult a HCP, or that they had already consulted a HCP for the same problem and knew what to do.

DISCUSSION

In this study on a large representative sample of the European general population, 30.3% of participants had consulted a dermatologist during the previous 2 years. The main reasons for consultation were skin cancer screening including mole check, and chronic skin diseases. Skin infections accounted for only a small proportion of dermatological visits. Similarly, in a study on dermatological consultations in Scotland,[9] the most frequent diseases were benign and malignant tumours, followed by eczema and psoriasis. Patients with skin infections, and acute skin problems in general, frequently refer for consultation to GPs.[4,7]

The percentage of people who consult a HCP for skin diseases differs depending on the severity and the nature of the

TABLE 1 Description of sociodemographic and clinical characteristics of participants ($n = 44,689$).

Variable	Level	*n*	%	SD
Sex	Male	21,887	49.1	0.46
	Female	22,802	50.9	0.46
Age (years)	18–24	4700	10.5	0.38
	25–34	7709	17.0	0.35
	35–44	8139	17.9	0.36
	45–54	8588	19.3	0.37
	55–64	8007	17.8	0.36
	65 +	7546	17.4	0.35
Living area	Urban area of a big city	17,390	37.3	0.45
	Suburban area outside a big city or in a medium-sized city	13,930	32.1	0.43
	Rural area or small town	13,369	30.6	0.43
Comorbidities	Bone and joint diseases	7767	16.4	0.34
	Cardiovascular diseases	4338	8.9	0.26
	Diabetes or endocrine or metabolic diseases	4015	9.0	0.27
	Gastrointestinal disorders	7134	16.2	0.34
	Neurological diseases	2472	5.2	0.21
	Psychiatric disorders	1819	4.1	0.18
	Psychological problems (anxiety, depression)	7001	15.2	0.33
	Respiratory diseases	4955	11.0	0.29
	Urinary and genital diseases	3364	7.3	0.24
Presence of skin diseases	At least one condition, disease, or unpleasant sensation	22,986	50.9	0.46
	At least one condition or disease	21,401	47.2	0.46
	At least one condition or disease except mole screening	19,915	43.4	0.46
Skin diseases in the previous 12 months	Acne	2452	5.4	
	Alopecia (all types)	3574	8.0	
	Atopic dermatitis. eczema	2385	5.3	
	Fungal skin infection (including tinea)	4534	10.1	
	Psoriasis	1758	3.9	
	Rosacea	865	1.9	
	Sexually transmitted diseases	1258	2.8	
	Skin cancer	681	1.5	

disease. In our study, we observed that more than 70% of people with atopic dermatitis, fungal infections, psoriasis, rosacea, and STD consulted a doctor, while about two third consulted for acne and only about one in two did so for alopecia. The reasons for not consulting were various. In particular, a high percentage of participants with alopecia thought that the disease was not worrying and not worth going to a doctor, while patients with psoriasis often answered that they were able to manage the disease since they had already consulted a doctor. Mostly patients with acne and fungal infection thought they were able to manage the disease by themselves. Avoidance of medical care has been defined as "keeping away from something [in a medical context] that is thought to cause mental or physical distress.[10] A qualitative analysis of reasons for avoiding medical care[11] detected three main aspects: the belief that seeking medical care was unnecessary, the presence of obstacles limiting access to it, and unfavourable evaluations of seeking medical care (i.e. interpersonal and medical factors related to the physician, organizational aspects, affective concerns and expected medical outcomes). In this report we focused on the first aspect.

In the presence of skin symptoms, one may choose to consult either the GP, or directly the dermatologists or other specialists. The GP may make the diagnosis and manage the disease or refer the patient to another specialist. We observed that approximately between 20% and 30% of people with skin diseases consulted their GP, except for fungal infection, where the percentage was about

TABLE 2 Percentage of participants answering to the question 'last time you consulted a dermatologist was roughly…?'

Dermatological consultation	*n*	%	SD
1 year ago or less	7956	18.4	0.36
1 to 2 years ago	5095	11.9	0.30
2 to 3 years ago	4953	11.4	0.29
3 to 5 years ago	3614	8.0	0.25
more than 5 years ago	7937	17.3	0.35
I have never seen a dermatologist	15,134	33.1	0.44

TABLE 3 For what problem did you consult the dermatologist?

	n	%	SD
Mole control or skin cancer screening	3643	22.3	0.61
Recurrent and long-lasting skin disease	2966	16.2	0.54
Acute or transient skin problem	2226	12.0	0.47
Cosmetic or aesthetic reasons	1834	9.6	0.43
Brown or dark stains or spots (e.g. melasma, chloasma) or birth marks (e.g. angioma, haemangioma)	1637	8.9	0.42
Nail, scalp or hair disorders	1392	7.7	0.39
Infectious skin problems due to a fungus, a parasite, a bacterium or a virus	1293	6.9	0.37
Keratoses or skin growths	890	4.7	0.31
Mucosal disorder such as ulcers, pimples or sores	542	2.9	0.25
Skin cancer	415	2.4	0.23
Chronic wounds or troubles associated with chronic venous insufficiency	392	2.1	0.21
Sexually transmitted disease	320	1.6	0.19

Note: *N* = 18,004 people who declared that they had seen a dermatologist in the previous 3 years.

40%. In contrast, most patients with STD consulted other specialists. It has to be considered that specialty qualification may differ from one country to another. For example, in the UK and Ireland, dermatology and venereology are separate specialties, and thus in case of anogenital diseases, people directly consult a venereologist. According to a recent study[12] on the content and conduct of GP consultations for dermatology problems, most skin problems were not referred to secondary care, and the GPs often subscribed a treatment. In fact, in our study we observed that the proportion of GPs who made the diagnosis was only slightly lower than the proportion of GPs who were consulted at first, suggesting that the GP usually made the diagnosis without referral to the dermatologist. Reasons of referral from GPs to dermatologists are influenced by several parameters. In a Danish study,[13] it was observed that referral frequency was inversely associated with the distance to the dermatologist, but in that study there was no information on therapeutic and diagnostic uncertainty, which are the main reasons for referral.[5] The diagnostic accuracy of skin diseases in primary care has been discussed in the literature,[14] in particular analysing the concordance between GPs and dermatologists. In an Australian study of 656 referrals,[15] the diagnostic concordance between the referring GPs and the dermatologists (with histopathological study when required) was 42%, with higher diagnostic accuracy in acne, warts, alopecia areata and benign naevi than other skin diseases. In our study, the diagnosis was made and confirmed by the first clinician in most cases, as the study is dealing with common skin diseases. However, in about 20% of cases, and in almost 40% for skin cancer and STD, the diagnosis was completely confirmed only after consultation with other doctors. Another important information arising from our study is that approximately 50% of diagnoses were made in private practice, and 50% in the framework of the corresponding national health service. The proportions may be different from one country to another, due to differences in healthcare systems, but this analysis is beyond the scope of the present report.

The sequence of patient's experiences from seeking for a HCP to consultations, diagnosis, treatment, and follow-up represents the so-called patient journey. In the present study, we focused on the first part of the journey, from first consultation to diagnosis, in patients with different skin diseases. Literature on the dermatological patient journey is still scarce. For example, in psoriasis, a single case has been described from the patient's and the doctor's points of view,[16,17] and other studies have analysed the patient journey towards biologics or oral treatment.[18,19] Patient journey in acne has been recently explored in The Netherlands,[20] where 58 different pathways through the healthcare system were described, showing that standardized patient pathways across different levels of care and specialisms are lacking. An analysis of the patient journey in atopic dermatitis[21] reported a lack of consensus on patients' trajectory through diagnosis, treatment, and long-term management. In some particular diseases, the pathway may be treacherous, as, for example, in hidradenitis suppurativa,[8] where diagnostic delay is often protracted and treatment complex.

The main limitation of this study is that all data were collected through questionnaires. Thus, diagnoses were based on self-reporting by participants, and we did not have any information either on the severity of the disease or on other clinical characteristics which may be associated to HCP consultation. On the other side, this methodology allowed to reach also people who do not undergo regularly a clinical consultation, and thus to obtain data from the general population instead that from a selected population of dermatological patients.

Mapping patient journeys may provide important insight into the value of healthcare services. Based on patients' experiences, providers can address the needs of the patient with

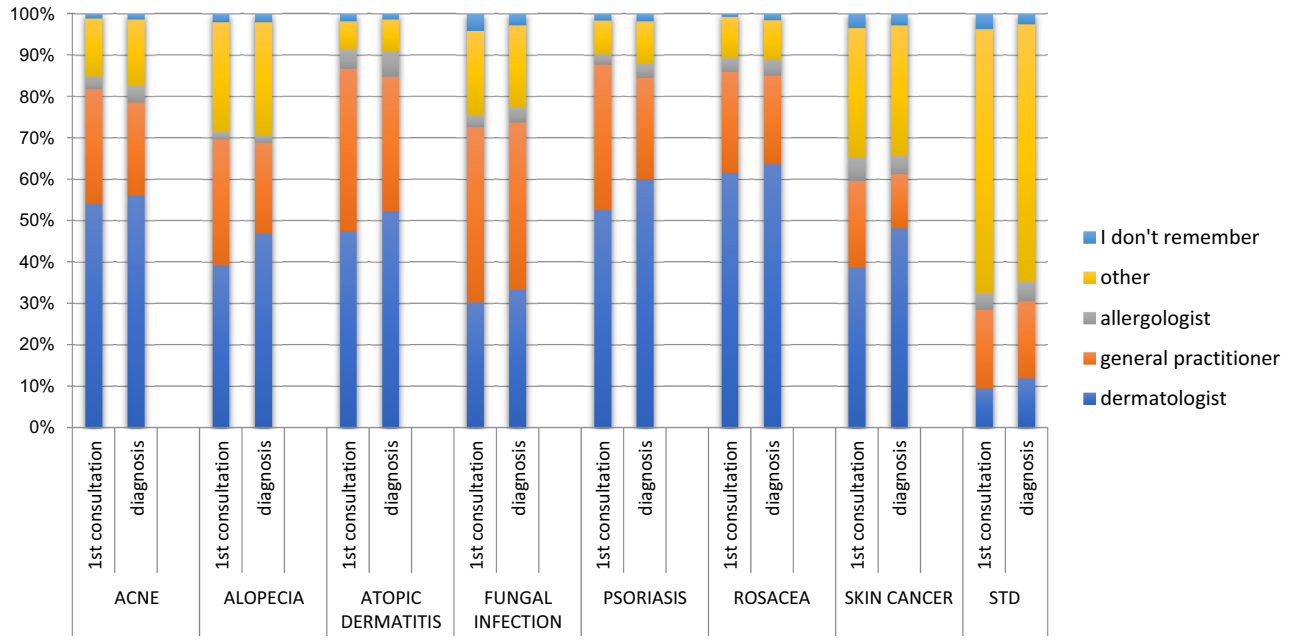

FIGURE 1 Frequencies of clinicians who were first consulted and of those who made the diagnosis in patients with different skin diseases.

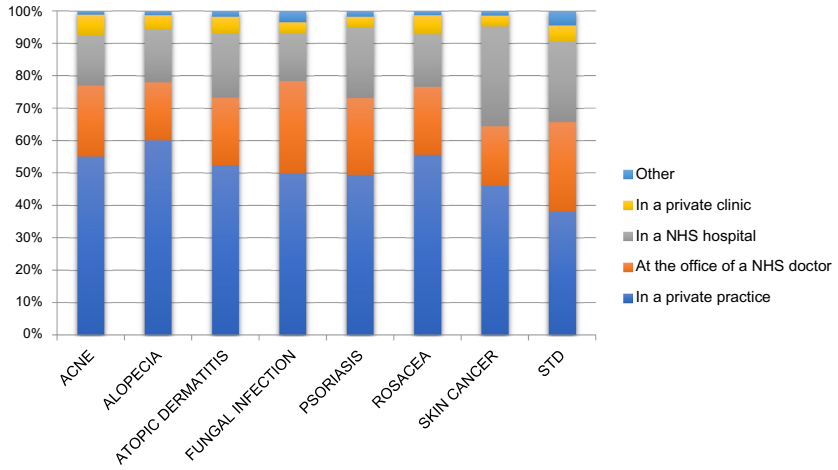

FIGURE 2 Site of the first diagnosis by the dermatologist in patients with different skin diseases.

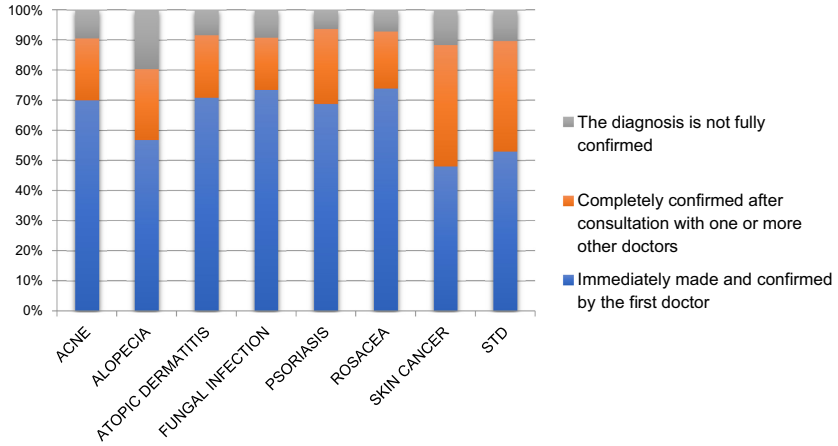

FIGURE 3 Frequencies of the answers to the question 'When was the diagnosis confirmed?' in patients with different skin diseases.

TABLE 4 Reasons for not consulting a healthcare professional in patients with different skin diseases.

	Acne	Alopecia	Atopic dermatitis	Fungal infection	Psoriasis	Rosacea	STD
Percentage of respondents who did not consult a healthcare professional	36.4	44.7	21.9	30.0	17.7	22.9	11.9
Reasons for not consulting (more answers were possible):							
I can handle this on my own or with relatives (%)	**47.2**	37.8	**40.8**	**53.4**	37.2	**39.6**	**42.8**
It wasn't worrying enough to consult a healthcare professional (%)	46.7	**53.7**	32.6	31.4	34.5	38.5	27.3
I can handle this on my own (%)	41.1	30.2	35.6	48.2	33.7	31.0	28.6
I've already consulted a healthcare professional for the same problem and now I know what to do (%)	21.7	14.4	37.4	24.8	**39.7**	31.5	36.4
I have someone close to me who knows this problem well and who advises me (%)	7.4	8.2	6.0	6.2	4.2	8.6	15.0

Note: Rank: 1: . 2: . 3: . 4: . 5: .
Bold indicates rank 1.

targeted interventions. Streamlining the patient journey by providing to guidelines for primary and secondary care across specialisms can improve patients' outcomes, and reduce diagnostic delay and health care expenses.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

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

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