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Investigating psoriasis awareness among patients in Italy: validation of a questionnaire

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Abstract. – OBJECTIVE: Psoriasis can have a profound impact on quality of life (QoL) and an awareness of the processes of the disease and its treatment is important in coping with symptoms. Patients do not always understand the potential consequences of their disease and the wide range of effective treatment strategies now available. We designed and validated a questionnaire to investigate patient awareness and understanding of psoriasis including pathogenesis, diagnosis, prognosis and treatment.

PATIENTS AND METHODS: This was a multicentre, cross-sectional investigation involving 14 psoriasis referral centres in Italy. The focus group technique was used by a panel of experts in psoriasis, to draw-up a list of questions exploring pathogenesis, diagnosis, prognosis, factors influencing clinical course of psoriasis as well as QoL issues and sources of information on their condition. Psychometric properties of the questionnaire were tested on a sample of 240 adult patients with psoriasis (including treatment-naïve and -experienced patients).

RESULTS: The mean age of patients was 50.3±14.9 years and 34.2% were female. The median time from diagnosis was 13.7 years (IQR 7.3-23.2). The Cronbach alpha was 0.77 and all items showed higher correlations within their own dimensions than to other dimensions. Each domain of awareness was well represented by a single dimension. Mean overall awareness was 59.7±13.1 on a 100-point scale.

CONCLUSIONS: Our questionnaire was valid in assessing patient awareness in five relevant areas of psoriasis, and can be useful in both the clinical setting and research studies to evaluate patients' knowledge of psoriasis better, with the final aim of reducing the burden of this chronic condition.

Key Words:
Psoriasis, Awareness, Questionnaire, Validation, PAP Questionnaire.

Introduction

Psoriasis, a common chronic dermatological condition, can have a profound impact on quality

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of life (QoL) and is associated with a wide range of comorbidities[1,2]. The burden of psoriasis is multifaceted and includes psychological, social and financial influences that impinge on patients' families, healthcare systems and ultimately on society as a whole[3]. In chronic conditions such as psoriasis, and particularly in the current healthcare context of shared decision-making between patients and their treating physicians, effective self-management is fundamental in obtaining clinical outcomes, and patient education provides the foundation of clinical management[4]. Awareness about a disease and its treatment is important in learning how to live with chronic symptoms and it has the eventual effect of improving self-empowerment and ameliorating QoL[5].

A common finding among clinicians treating psoriasis is despite years of symptomatic disease and treatment, many patients still lack a real understanding of the severity of their disease, its potential consequences and new treatment options that have become available in recent years[6]. Educational tools have been shown to improve 'awareness' of psoriasis[7,8], but educational interventions need to translate into improved clinical outcomes, mediated by improved patient awareness via health advocacy groups and peer-to-peer support[9-11]. The assessment of effectiveness of a given intervention depends on having a reliable tool with which to measure baseline levels of the outcome measure (in this case, awareness on psoriasis) and that is sensitive to change after the intervention – such a tool would also be useful in daily clinical practice[12,13]. Awareness is also driven by the cultural context in which patients live, and instruments to measure it should take this into account[14]. A number of studies have been published on how much patients with psoriasis know about their disease, but data from Italy are limited[15-18].

The aim of this study is to design and validate an updated tool to investigate patient awareness and understanding of psoriasis in several domains (pathogenesis, diagnosis, prognosis and treatment). The tool is designed for use both in the clinical setting – enabling clinicians to identify patient-specific needs and to tailor communication accordingly – and in research studies to investigate factors associated with patient compliance and QoL.

Patients and Methods

This was a multicentre, cross-sectional study conducted in 14 referral centres for psoriasis across Italy. All patients gave written informed consent and the local Ethics Committee of each centre approved the study and it conformed with the Declaration of Helsinki 1975 (revised in 1983).

Stage 1: Questionnaire Development

The panel of 14 dermatologists, who were experts in psoriasis, used the focus group technique to develop a list of questions (in Italian) covering a wide range of topics including knowledge of pathogenesis, diagnosis, prognosis, factors influencing clinical course of their disease and sources of information (including a question with seven sub-items) as well questions addressing common misunderstandings in clinical practice. Two additional items were added to explore the psychological impact of their disease on QoL, followed by three open questions (Table I).

The questionnaire was designed for patient self-administration to ensure clinicians/healthcare personnel did not influence responses. Subsequently, a psychologist, experienced in the patient–clinician relationship, reviewed all the questions. The questionnaire was administered to a test sample of patients (n=10), to check completeness, legibility, comprehension and ease of response.

Answers were coded on a four-point Likert scale – scoring 0-3, from low to high awareness: 0=wrong answer, 1=unsure but wrong, 2=unsure but correct, 3=correct answer), apart from one item that was coded as yes/no and for question 23 for which none or 1 'yes' was coded 0; 2 or 3 'yes answers' were coded 1; 4 or 5 were coded 2 and 6 or 7 were coded 3 (Table I). The questionnaire was specially designed for self-administration and patients received a coding-free version, to avoid influencing responses. Scoring of the questionnaire within each domain was calculated by adding up individual items' scores standardized on the highest possible score for that domain, and multiplied by 100 for readability.

Stage 2: Questionnaire Validation

From June 2013 to January 2014, consecutive patients evaluated at the participating centres (Appendix 1) were enrolled in the study if they met inclusion criteria. Inclusion criteria were: aged >18 years, with a confirmed diagnosis of psoriasis. The calculated sample size was 190 patients, based on a target Cronbach's alpha of 0.8 (vs 0.7, considered low) in a questionnaire with 4-6 items per domain (23 items overall) with power 90% and alpha error 1%. Sample size calculations were made with PASS 11 software (Hintze, J. 2011. PASS 11. NCSS, LLC. Kaysville, UT, USA. www.ncss.com).

Table I. Questionnaire, coding of answers and domains.

This questionnaire is designed to help us understand what worries you about psoriasis so that we can help you to get to know more about your disease and its treatment. Thank you for agreeing to take part.

Instructions: below you will now find questions that people with psoriasis often ask. Please mark with an X the answer that best describes how you feel and think.

Area	Item – question			
Pathogenesis	**1.**	**Is psoriasis contagious?**		
	No	Probably not	I think so	Definitely yes
	3	2	1	0
Pathogenesis	**2.**	**Do you think you may have inherited psoriasis from a member of your family, or that you can pass it on to your children?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Prognosis	**3.**	**Do you think you can definitely recover from psoriasis?**		
	No	Probably not	I think so	Definitely yes
	3	2	1	0
Diagnosis	**4.**	**Can psoriasis affect other body systems, apart from the skin?**		
	No	Probably not	I think so	Definitely yes
	0	1	2	3
Diagnosis	**5.**	**Do you consider psoriasis to be a severe disease?**		
	No	Probably not	I think so	Definitely yes
	0	1	2	3
Clinical course	**6.**	**Do you think your diet can influence your psoriasis?**		
	No	Probably not	I think so	Definitely yes
	0	1	2	3
Clinical course	**7.**	**Do you think your psoriasis can worsen if you drink alcohol or smoke cigarettes?**		
	No	Probably not	I think so	Definitely yes
	0	1	2	3
Pathogenesis	**8.**	**Do you consider psoriasis a form of allergy?**		
	No	Probably not	I think so	Definitely yes
	3	2	1	0
Clinical course	**9.**	**Can your psoriasis improve with sun exposure?**		
	No	Probably not	It depends on my skin's features	Yes
	0	1	3	2
Source of information	**10.**	**Do you know any psoriasis patients associations?**		
	No	Yes		
	If yes, specify:.....			

Table continued

Table I (Continued). Questionnaire, coding of answers and domains.

This questionnaire is designed to help us understand what worries you about psoriasis so that we can help you to get to know more about your disease and its treatment. Thank you for agreeing to take part.

Instructions: below you will now find questions that people with psoriasis often ask. Please mark with an X the answer that best describes how you feel and think.

Area	Item – question			
Clinical course	**11.**	**Can any infections worsen psoriasis?**		
	No	Probably not	I think so	Definitely yes
	0	1	2	3
Clinical course	**12.**	**Are there any drugs that can worsen psoriasis?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Clinical course	**13.**	**Can body-care products, such as soaps, body lotions and shower gels, worsen psoriasis?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Pathogenesis	**14.**	**How much can anxiety and stress cause or worsen psoriasis?**		
	Not at all	Very little	A little	A lot
	0	1	2	3
Diagnosis	**15.**	**Are there other diseases that can be associated with psoriasis?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
	If yes, specify:.....			
Prognosis	**16.**	**Can psoriasis cause fingernails and toenails to fall** off?		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Prognosis	**17.**	**Can psoriasis make you lose your hair?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Clinical course	**18.**	**Can your body weight increase with psoriasis?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Diagnosis	**19.**	**Can psoriasis affect bones?**		
	No	Probably no	I think so	Definitely yes
	0	1	2	3
Quality of life	**20.**	**How much can psoriasis influence your mood/psychological state?**		
	Not at all	Very little	A little	A lot
	0	1	2	3

Table continued

Table I (Continued). Questionnaire, coding of answers and domains.

This questionnaire is designed to help us understand what worries you about psoriasis so that we can help you to get to know more about your disease and its treatment. Thank you for agreeing to take part.

Instructions: below you will now find questions that people with psoriasis often ask. Please mark with an X the answer that best describes how you feel and think.

Area	Item – question
Source of information	**21. How informed are you on possible drugs or care options for psoriasis?**

Not at all	Very little	A little	A lot
0	1	2	3

List here drugs and care options you know:

Area	Item – question
Quality of life	**22. Would you like to talk with an expert (doctor, psychologist, etc.) about your problems with psoriasis?**

Not at all	Very little	A little	A lot
0	1	2	3

Source of information — **23. Have you heard about psoriasis from:**

a. Newspapers	No	Yes
b. TV	No	Yes
c. Radio	No	Yes
d. Internet	No	Yes
e. Friends/relatives	No	Yes
f. Family doctor	No	Yes
g. Pharmacist	No	Yes

Patients completed the questionnaire before their scheduled outpatient visit, after giving written consent to participate. Patients were given 15±10 minutes to complete the questionnaire. The time taken to complete all questions having been tested in advance on a random subsample of 40 patients. The actual time for completion of questionnaires was recorded.

In the follow-up medical examination physicians completed the patient case form (Appendix 2) including demographic data, history, clinical features, co-morbidities, lifestyle and treatment. The Dermatology Life Quality Index (DLQI) questionnaire was administered during the visit as well as the Psoriasis Area and Severity Index (PASI)[19]. Data were entered into a specially designed database by dedicated personnel; data monitoring and quality checks ensured that missing, inconsistent and invalid data were resolved on a continuous basis.

Statistical Analysis

Descriptive statistics were obtained for all variables: mean and standard deviation (or median and interquartile range) for continuous variables, absolute frequencies and percentages for categorical variables.

Internal validity of the questionnaire was evaluated by assessing:

- Completeness and proportion of upper and lower limits of each item.
- Descriptive statistics of each item.
- Reliability (Cronbach's alpha) for internal consistency for each dimension and the overall scale.

Multi-trait/multi-item correlation matrices to assess convergent and discriminant ability (construct validity) and consistency (item-rest of scale correlation), of each item and dimensions.

External validity was assessed by means of Spearman's rho correlation of items, dimensions and overall scale with age, duration of psoriasis and DLQI. Univariate and multivariate linear regression models were fitted to assess the association between awareness and a number of predictors; for the multivariate analysis, only those variables significant at univariate analysis with $p < 0.05$ were retained, with no further refinements. Finally, principal component analysis was used for dimensionality.

Results

During the study period a total of 240 patients were enrolled in participating centres and a detailed clinical and social history together with co-morbidities of each patient was obtained (Tables II and III). Completeness, ceiling and floor effect, and descriptive statistics for each item and dimension are reported in Table IV. A total of 207 (86%) patients answered all the items. Median time for questionnaire admin-

Table II. Demographic characteristics of patients (n=240) at baseline [Data are n (%) unless otherwise specified].

Variable	All patients	N	%
Age (mean ± SD years)		50.3	(14.9)
Female sex		82	34.17
Nationality	Italian	233	97.08
Educational level/Qualifications	None	1	0.42
	Primary school	27	11.25
	Middle school	75	31.25
	High school diploma	93	38.75
	Degree	39	16.25
	Post degree	5	2.08
Geographic area	North	86	35.83
	Centre	78	32.50
	South	35	14.58
	Major islands	41	17.08
Housing	Coast	86	35.83
	Inland	147	61.25
	Other	7	2.92
Exposure to sunlight (hours/day) Spring/Summer	Median (IQR)	3	(2-5)
Exposure to sunlight (hours/day) Autumn/Winter	Median (IQR)	1	(0-2)
Fruit servings (per week)	Median (IQR)	7	(3-7)
Vegetable servings (per week)	Median (IQR)	6	(3-7)
Time from symptoms onset to diagnosis (months)	Median (IQR)	1	(0-20)
Time from symptoms onset to enrolment (years)	Median (IQR)	16.3	(8.8-23.8)
Time from diagnosis to enrolment (years)	Median (IQR)	13.7	(7.3-23.2)
Living arrangements	Alone	41	17.08
	With family	195	81.25
	Other	2	0.83
	Not known	2	0.83
Internet usage	Yes	177	73.75
Other member(s) of the family with psoriasis	No	81	33.75
	Yes	141	58.75
	Not known	18	7.50
Organ systems involved	Skin	232	96.67
	Bone and joint	87	36.25
	Nails	138	57.50
	Scalp	160	66.67
	Perineum	61	25.42
Current treatment of psoriasis	Yes	188	78.33
	Topical	111	59.04
	Systemic	126	67.02
	Phototherapy	29	15.43

Table III. Reported comorbidities of patients (n=240) at baseline. [Data are n (%) unless otherwise specified].

Co-morbidity	All patients	N	%
Obesity	No	191	79.58
	Yes	46	19.17
	Not known	3	1.25
Hypertension	No	150	62.50
	yes	88	36.67
	Not known	2	0.83
	Treated	44	18.33
Diabetes mellitus	No	210	87.50
	Yes	26	10.83
	Not known	4	1.67
	Treated	13	5.42
Liver steatosis	No	212	88.33
	Yes	20	8.33
	Not known	8	3.33
	Treated	1	0.42
Uveitis	No	231	96.25
	Yes	6	2.50
	Not known	3	1.25
	Treated	0	
Cardiovascular	No	208	86.67
	Yes	30	12.5
	Not known	2	0.83
	Treated	13	43.33
Dyslipidaemia	No	163	67.92
	Yes	74	30.83
	Not known	3	1.25
	Treated	20	27.03
Chronic inflammatory bowel disease	No	223	92.92
	Yes	11	4.58
	Not known	6	2.50
	Treated	4	36.36
Depression	No	208	86.67
	Yes	28	11.67
	Not known	4	1.67
	Treated	10	35.71
Alcohol abuse	Yes	38	15.83
	Treated	2	5.26
Current smoking	Yes	85	35.42
	Treated	1	1.18
Other comorbidities/ risk factors	Yes	6	2.50
	Treated	2	33.33

istration was 8 minutes (IQR 5-13). When taken individually, Cronbach's alpha of the whole scale was 0.77, and 0.34, 0.51, 0.68, 0.54, 0.41 and 0.33 for pathogenesis, diagnosis, clinical course, prognosis, QoL and general sources of information, respectively. Multi-trait/multi-item correlation matrices (item-rest, item-scale correlation and Cronbach's alpha) for each item and dimension are presented in Table V. All items showed higher correlations within their own dimension than to other dimensions (Table VI). Awareness was inversely correlated to age, and positively correlated with QoL as measured by DLQI, whereas duration of disease was in between the two. The univariate and multivariate association between awareness and number of predictors showed the highest associations were with age, gender, clinical depression and presence of another affected member of the family (Table VII). Factorial analysis (scree and loadings plots) for the four areas of knowledge (plus QoL and sources of information) in the overall cohort of patients (n=240) is shown in Figure 1. The scree plot, useful in deciding how many dimensions are represented by the data, plots dimensions as the X-axis and the corresponding eigenvalues (variance) as the Y-axis (the dimension with the largest eigenvalue has the most variance, dimensions with smaller or negative eigenvalues are negligible; traditionally, only eigenvalues of >1 are considered relevant). Across subsequent dimensions eigenvalues decline – the number of dimensions necessary to explain the data is indicated by the number of dimensions before the 'elbow' (the point where the slope of the curve flattens out). In our questionnaire, each area of awareness is well represented by a single dimension. Similarly the loadings (correlations of the items with the dimension) for the two dimensions with highest variance in each area of awareness are shown. Most items are similarly correlated to the first dimension, and unevenly correlated with the second dimension retained in the analysis. These plots, as well as confirming the findings from the multi-trait/multi-item analysis, support the correct dimensionality of the questionnaire. For two areas, those with only one dimension with eigenvalue >1, it was not possible to generate the corresponding plot.

Regarding internal validity, the new PAP (Patient's Awareness in Psoriasis) questionnaire, demonstrated good performance, because of its good internal consistency (alpha 0.77 for the whole scale, which decreased when individual dimensions were considered), its ease of administration even in the busy clinical routine (almost all items of this self-completed form were answered completely), its statistical properties (all dimensions had a normal distribution), its meaningful item-dimension matrix of correlations (correlation of items to their domain was always higher than to other domains) and its correct dimensionality (factor analysis showed that all domains were correctly represented).

Table IV. Completeness, ceiling and floor effect, and descriptive statistics for each item and dimension.

Item/ domain	N (%) answered	N (%) ceiling	N (%) floor	Mean	SD	Min	P25	Median	P75	Max
Item 1	240 (100)	5 (2.1)	203 (84.6)	2.78	0.58	0	3	3	3	3
Item 2	236 (98.3)	37 (15.4)	98 (40.8)	1.93	1.10	0	1	2	3	3
Item 8	239 (99.6)	12 (5.0)	174 (72.5)	2.55	0.84	0	2	3	3	3
Item 14	239 (99.6)	12 (5.0)	91 (37.9)	2.20	0.79	0	2	2	3	3
Pathogenesis		2 (0.8)	26 (10.8)	78.44	16.1	33.33	66.7	83.33	91.67	100
Item 4	237 (98.8)	33 (13.8)	136 (56.7)	2.19	1.10	0	2	3	3	3
Item 5	239 (99.6)	52 (21.7)	76 (31.7)	1.70	1.13	0	1	2	3	3
Item 15	235 (97.9)	54 (22.5)	49 (20.4)	1.43	1.06	0	1	1	2	3
Item 19	238 (99.2)	11 (4.6)	156 (65)	2.45	0.87	0	2	3	3	3
Diagnosis		4 (1.7)	22 (9.2)	64.13	22.2	8.33	50	66.67	83.33	100
Item 6	240 (100)	42 (17.5)	69 (28.7)	1.7	1.07	0	1	2	3	3
Item 7	237 (98.8)	25 (10.4)	87 (36.3)	2.00	0.97	0	1	2	3	3
Item 9	239 (99.6)	19 (7.9)	33 (13.8)	1.90	0.73	0	2	2	2	3
Item 11	234 (97.5)	23 (9.6)	70 (29.2)	1.85	0.96	0	1	2	3	3
Item 12	229 (95.4)	35 (14.6)	52 (21.7)	1.55	1.01	0	1	1	2	3
Item 13	240 (100)	41 (17.1)	74 (30.8)	1.69	1.08	0	1	2	3	3
Item 18	236 (98.3)	41 (17.1)	66 (27.5)	1.67	1.06	0	1	2	3	3
Clinical course		1 (0.4)	3 (1.3)	58.04	19.5	4.76	42.9	59.52	71.43	100
Item 3	240 (100)	15 (6.3)	97 (40.4)	2.17	0.86	0	2	2	3	3
Item 16	238 (99.2)	39 (16.3)	84 (35)	1.76	1.11	0	1	2	3	3
Item 17	237 (98.8)	77 (32.1)	42 (17.5)	1.18	1.08	0	0	1	2	3
Prognosis		7 (2.9)	20 (8.3)	56.39	24.51	0	44.44	55.56	77.78	100
Item 20	237 (98.8)	14 (5.8)	89 (37.1)	2.08	0.89	0	2	2	3	3
Item 22	237 (98.8)	99 (41.3)	42 (17.5)	1.17	1.16	0	0	1	2	3
Quality of Life		11 (4.6)	25 (10.4)	53.54	27.4	0	33.3	50	66.67	100
Item 10	238 (99.2)	184 (76.7)	54 (22.5)	0.23	0.42	0	0	0	0	1
Item 21	238 (99.2)	21 (8.8)	37 (15.4)	1.81	0.80	0	1	2	2	3
Item 23	240 (100)	36 (15.0)	48 (20.0)	1.61	0.97	0	1	2	2	3
Source of information		3 (1.3)	5 (2.1)	25.89	10.8	0	21.4	28.57	35.71	50
Whole scale		0	1 (0.4)	59.72	13.0	20.29	51.4	60.87	68.84	92.75

SD: standard deviation; p25 25th percentile; p75: 75th percentile.

Discussion

We developed and validated the PAP questionnaire – investigating patient perceptions of psoriasis in a wide range of areas/domains, based on the clinical experience of psoriasis experts, patients and a psychologist. In a chronic condition such as psoriasis, patient perception is pivotal for correct decision-making and compliance to therapy[20]. Lack of knowledge about side effects ranks high among reasons for non-compliance to therapy[21,22]. In addition, smoking and other modifiable cardiovascular risk factors for severe psoriasis are amenable to control by improving patient awareness/involvement[23].

Psoriasis can have a profound effect on QoL and there are a number of tools available to measure QoL including the Short Form-36[24-26], Sickness Impact Profile[27], Nottingham Health Profile[28] and General Health Questionnaire[29]. The DLQI[28,30] and Skindex-29[31] are not sensitive enough to measure patient awareness and beliefs[3,31,32]. Qualitative studies show that patients expect, among other things, more information on psoriasis; whereas clinicians are aware (and it has been confirmed in quantitative studies), that patients not receiving adequate information have lower compliance and overall satisfaction with how their condition is managed[33,34,35].

There is an unmet medical need to adapt guidelines on the treatment of psoriasis for use by patients, with the aim of giving patients an overview of management options in terms of possible advice for optimal usage and strategies to deal with complications. The authors of recently published guidelines acknowledge this and state 'the timely provision of information and prompt induction of adequate therapy should help prevent severe disease'[36]. Recently, a patient decision aid for psoriasis was developed in partnership with patients, based on current clinical practice guidelines, to assist both patients and clinicians in selecting the most appropriate management options[37].

Table V. Multi-trait/multi-item correlation matrix.

		Patho-genesis	Diagnosis	Clinical course	Prognosis	Quality of life	General information
Pathogenesis	Item 1	0.5216	0.1601	0.1826	0.1302	–0.1837	0.1455
	Item 2	0.6629	0.2118	0.3264	0.1776	0.0564	0.0653
	Item 8	0.5989	0.2211	0.1164	0.0513	–0.0492	0.0319
	Item 14	0.477	0.0961	0.1277	0.0713	0.0225	0.1047
Diagnosis	Item 4	0.284	0.7112	0.3118	0.2874	0.1488	0.187
	Item 5	0.0278	0.68	0.1985	0.2689	0.3005	0.07
	Item 15	0.2164	0.5997	0.3675	0.2798	0.1245	0.1931
	Item 19	0.31	0.5314	0.232	0.3101	0.014	0.2603
Clinical course	Item 6	0.302	0.2069	0.6618	0.0468	0.1004	0.1569
	Item 7	0.2551	0.3109	0.6984	0.1689	0.1659	0.156
	Item 9	0.1155	0.1467	0.3378	–0.0031	0.0071	–0.0116
	Item 11	0.1295	0.252	0.5182	0.2799	0.1716	0.1216
	Item 12	0.2957	0.3151	0.6911	0.2277	0.1225	0.0741
	Item 13	0.1244	0.1471	0.4836	0.2073	–0.0335	0.223
	Item 18	0.2191	0.3983	0.6506	0.3236	0.1302	0.1614
Prognosis	Item 3	0.2142	0.296	0.1454	0.6034	0.1344	–0.0354
	Item 16	0.0743	0.3834	0.2486	0.7994	0.1049	0.246
	Item 17	0.168	0.228	0.2315	0.7425	0.0643	0.1929
Quality of life	Item 20	–0.0265	0.2814	0.1972	0.1592	0.7295	0.136
	Item 22	–0.0027	0.1596	0.1239	0.1163	0.8439	0.0527
Source of information	Item 10	0.0947	0.1532	0.1085	0.0933	0.0532	0.3442
	Item 21	0.1794	0.249	0.272	0.2139	0.0399	0.7364
	Item 23	0.0506	0.1659	0.0628	0.1154	0.1153	0.7905

We know from the management of other chronic conditions such as diabetes and cardiovascular disease that education is essential for effective self-management. Patients who do not receive formal diabetes education not only have knowledge gaps but they also are more likely to develop chronic complications than those who have received prior instruction on their condition[38,39]. The American Association of Diabetes Educators AADE7™ framework, provides a benchmark for other chronic disease processes. It explores factors essential for effective self-management: healthy eating, physical activity, taking medications, monitoring, problem solving, reducing risks of acute/chronic complications, and psychosocial aspects of living with diabetes. Questions are not only about diabetes-related symptoms, but also include lifestyle factors, mental health status, psychosocial concerns, functional and health literacy, health beliefs, typical approaches to problem solving, and readiness for and barriers to learning[40]. In patients with coronary heart disease, it has been suggested that those who perceive themselves to be more susceptible to complications increase their prevention-seeking behaviour[41]. In cardiology, tools for the assessment of field-specific patient knowledge have been developed to tailor both treatment and education to the needs of individual patients[42-48]. For example, a nurse educational intervention improved knowledge of potential acute myocardial infarction symptoms and appropriate responses in cardiac rehabilitation up to 2 months after the intervention[49,50].

Table VI. Correlation (and p-value) of each domain and of the whole scale with age, duration of psoriasis and Dermatology Life Quality Index (DLQI) questionnaire response.

	Age	Duration of disease	DLQI
Pathogenesis	–0.24	–0.27	0.02
	<0.001	<0.001	0.786
Diagnosis	–0.14	–0.02	0.11
	0.028	0.716	0.099
Prognosis	–0.24	–0.13	0.08
	<0.001	0.048	0.238
Clinical course	0.00	0.02	0.18
	0.943	0.813	0.005
Quality of life	–0.13	0.19	–0.08
	0.043	0.004	0.245
Source of information	–0.07	0.04	0.18
	0.287	0.576	0.005
Whole scale	–0.24	–0.08	0.13
	<0.001	0.218	0.043

Table VII. Association between knowledge (as measured by our questionnaire) and a number of predictors.

Variable		Univariate			Multivariate		
	Category	Coefficient	95% CI	P-value	coefficient	95% CI	*p*-value
Age in years		– 0.217	– 0.328, –0.106	<0.001	–0.242	–0.368, –0.117	<0.001
Average sunlight hours per day in summer		0.293	– 0.232, 0.818	0.274			
Average sunlight hours per day in winter		0.158	– 0.955, 1.272	0.781			
Average fruit servings per week		– 0.157	– 0.554, 0.239	0.436			
Average vegetable servings per week		– 0.079	– 0.537, 0.380	0.737			
Months from symptoms onset to diagnosis		– 0.028	– 0.070, 0.014	0.185			
Years from symptoms onset to enrolment		0.121	– 0.022, 0.264	0.096			
Years from diagnosis to enrolment		0.154	0.009, 0.298	0.037	0.158	0.011, 0.305	0.035
Gender	Male	–	–				
	Female	6.496	3.029, 9.962	<0.001	5.311	1.999, 8.625	0.002
Nationality	Italian	1.530	– 8.512, 11.572	0.765			
Education/qualifications	None	–	–				
	Primary school	–12.990	–39.123, 13.144	0.330			
	Middle school	– 7.401	–33.234, 18.432	0.574			
	High school	– 7.293	–33.093, 18.507	0.580			
	Degree	– 4.794	–30.783, 21.196	0.718			
	Post degree	8.116	–19.996, 36.228	0.571			
Geographic area	North	–	–				
	Centre	– 2.259	– 6.340, 1.822	0.278			
	South	– 2.219	– 7.451, 3.014	0.406			
	Major islands	– 4.645	– 9.598, 0.308	0.066			
Housing							
	Coast	–	–				
	Inland	2.126	– 1.420, 5.673	0.240			
	Other	– 2.961	–13.229, 7.307	0.572			
Living arrangements							
	Alone	–	–				
	With family	4.107	– 0.315, 8.528	0.069			
	Other	9.049	– 9.588, 27.686	0.341			
Internet usage	No	–	–				
	Yes	3.168	– 0.652, 6.989	0.104			

Table continued

Table VII. (Continued). Association between knowledge (as measured by our questionnaire) and a number of predictors.

Variable		Univariate			Multivariate		
	Category	Coefficient	95% CI	P-value	coefficient	95% CI	*p*-value
Another member of the family affected	No	–	–				
	Yes	5.921	2.342, 9.50	0.001	4.013	0.602, 7.425	0.021
	Not known	4.679	– 2.011, 11.368	0.170	4.683	– 1.608, 10.974	0.144
Skin	No	–	–				
	Yes	–7.834	–17.196, 1.529	0.101			
Bone and joint	No	–	–				
	Yes	4.396	0.854, 7.938	0.015	3.761	0.263, 7.260	0.035
	Not known	0.115	– 7.150, 7.379	0.975	0.134	– 6.757, 7.026	0.969
Nails	No	–	–				
	Yes	2.593	– 0.803, 5.989	0.134	1.370	– 2.033, 4.775	0.428
	Not known	21.928	3.460, 40.395	0.02	16.550	– 3.376, 36.478	0.103
Scalp	No	–	–				
	Yes	4.185	0.639, 7.730	0.021	1.324	– 2.224, 4.873	0.463
Perineum	No	–	–				
	Yes	1.608	– 2.269, 5.484	0.416			
Obesity	No	–	–				
	Yes	1.767	– 2.535, 6.069	0.421			
	Not known	3.731	–11.510, 18.971	0.631			
Hypertension	No	–	–				
	Yes	–4.115	– 7.599, –0.631	0.021	– 2.579	– 6.238, –1.079	0.166
	Not known	–0.097	–18.565, 18.372	0.992	–14.267	–34.485, –5.951	0.166
Diabetes mellitus	No	–	–				
	Yes	1.449	– 3.999, 6.896	0.602			
	Not known	–3.930	–17.156, 9.296	0.560			
Liver steatosis	No	–	–				
	Yes	2.804	– 3.320, 8.928	0.369			
	Not known	–2.232	–11.661, 7.197	0.643			
Uveitis	No	–	–				
	Yes	3.344	– 7.480, 14.168	0.545			
	Not known	–6.801	–22.011, 8.409	0.381			
Cardiovascular	No	–	–				
	Yes	–4.499	– 9.589, 0.592	0.083			
	Not known	–4.257	–22.777, 14.263	0.652			

Table continued

Table VII. Association between knowledge (as measured by our questionnaire) and a number of predictors.

Variable		Univariate			Multivariate		
	Category	Coefficient	95% CI	P-value	coefficient	95% CI	*p*-value
Dyslipidaemia	No	–	–				
	Yes	–2.385	– 6.049, 1.279	0.202			
	Not known	–3.717	–18.947, 11.514	0.632			
Chronic inflammatory bowel disease	No	–	–				
	Yes	1.521	– 6.58, 9.621	0.713			
	Not known	1.521	– 9.33, 12.371	0.784			
Depression	No	–	–				
	Yes	6.142	0.923, 11.362	0.021	5.495	0.315, 10.675	0.038
	Not known	4.745	– 8.344, 17.834	0.477	0.381	–11.829, 12.591	0.381
Alcohol abuse	No	–	–				
	Yes	1.316	– 3.310, 5.943	0.577			
Current smoking	No	–	–				
	Yes	2.162	– 1.362, 5.685	0.229			
Other comorbidities/risk factors	No	–	–				
	Yes	2.192	– 8.629, 13.014	0.691			
Adequate dietary habits	No	–	–				
	Yes	3.009	– 1.694, 7.711	0.210			
	Not known	3.609	– 4.395, 11.612	0.377			
Current treatment of psoriasis	No	–	–				
	Yes	1.434	– 2.665, 5.532	0.493			

CI, confidence interval.

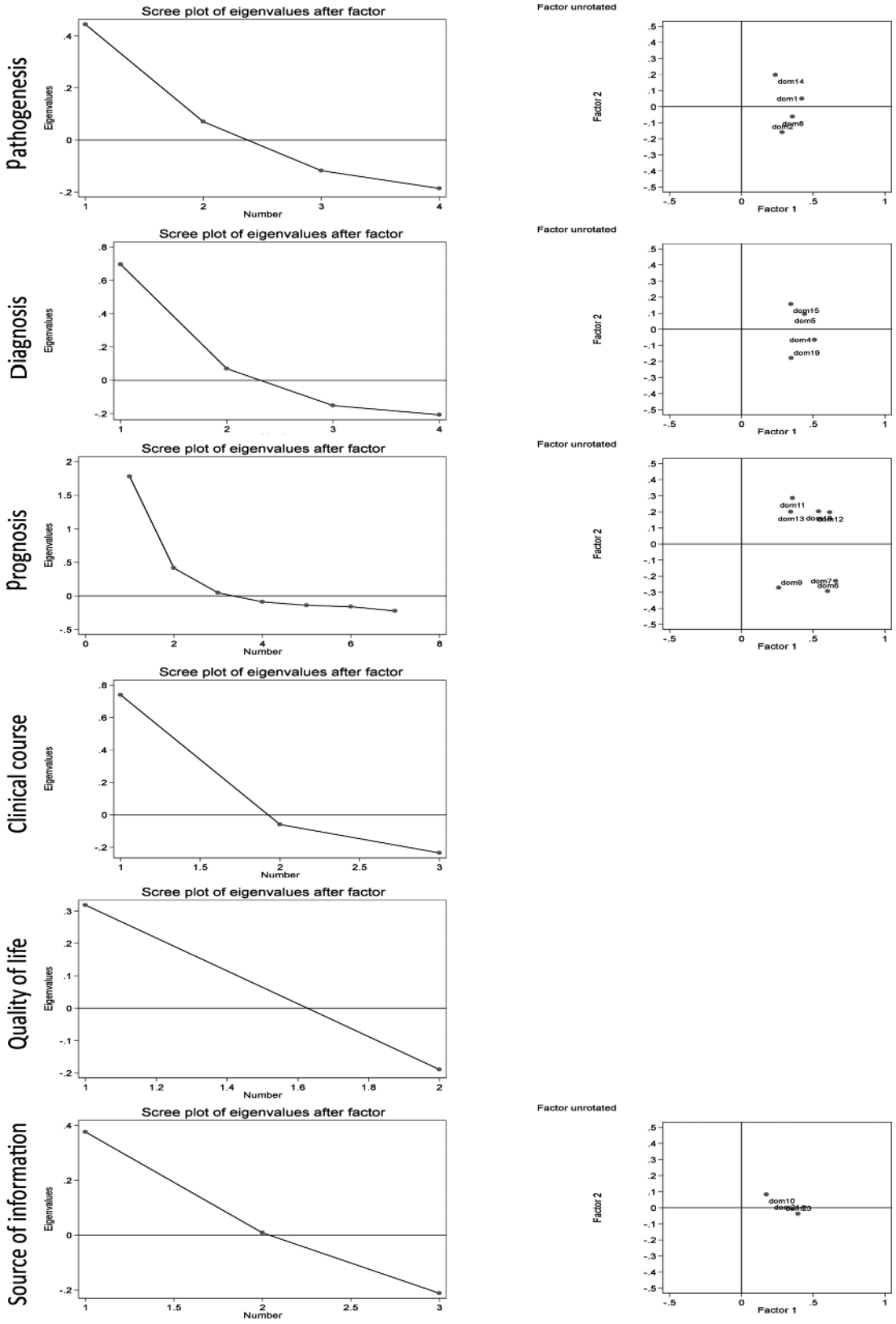

Figure 1. Factorial analysis: scree and loadings plots for the five areas of knowledge (plus quality of life and source of information) in patients with psoriasis (n=240).

It is evident therefore that physicians' awareness of patients' knowledge when formulating a patient-centred response, might not be sufficient to provide effective communication. The transfer of information from the healthcare professional to the patient with a chronic condition represents only the beginning of the process leading to successful self-care[51,52]. This paradigm has been named behavioural medicine, and ensuring that the patient receives adequate training and support to encourage self-management is at its foundation[53].

Historically, the validity of studies on the effectiveness of educational tools on psoriasis outcomes is hampered by the lack of a validated method to measure actual patient awareness.[8,54] Studies, mostly dating back to the 1990s, have analysed patients' perception of psoriasis[15-17]. In one study patients were asked to rate their knowledge of and experience with specific therapies for psoriasis from "never heard of" to 'use currently'[55]. Another using a short questionnaire (Psoriasis Empowerment Enquiry in the Routine Practice, PEER) exploring four items, identified three distinct factors (knowledge, experience, skills) needed for patient empowerment in self-management[54]. In general, a multi-item scale, with each item intended to measure a separate aspect of the same underlying construct, is more likely than a single-item measure to capture details of complex constructs[56]. Results of a recent study using a 49-item questionnaire was published in a pre-post study of patient education in the context of climate therapy[18]; however, the authors did not report the dimensionality of the questionnaire and did not attempt to separate areas of awareness.

In our patient sample, awareness of psoriasis in all domains was inversely correlated to age, with older patients showing lower scores. This might be explained by the fact that younger people are more self-conscious of their condition and try to learn more as a coping mechanism[57]. Female gender was associated with greater awareness – confirming results of a study conducted in Sweden showing that women needed more information than men[58]. Interestingly, awareness was only very weakly associated with QoL as measured by DLQI – providing further evidence that awareness is a component that requires specific assessment tools.

Strengths and Limitations

The strengths of our study are its large sample size, prospective design, and the small amount of missing data. In addition, very detailed patient case forms were completed adding to the overall body of knowledge. The study is not without its limitations. While it included a cross-section of patients in Italy, results cannot automatically be applied to other cultural contexts. Also, prospective validation, for example, measuring changes after an educational intervention would enhance its validity, but test–retest was not deemed to be reasonable in this context, because simply having read the items before the clinical visit and having discussed them during/after the visit with the clinician would render results invalid.

Conclusions

We designed and validated a questionnaire assessing patient awareness in five relevant areas of psoriasis, useful both in the clinical setting (enabling clinicians to tailor communication to patients and to identify patient-specific needs) and in research studies (e.g. to investigate factors associated with patient compliance, QoL or effectiveness of an educational intervention), with the final aim of reducing the burden of this chronic condition.

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Conflict of interest

The authors declare that they have no conflicts of interest that may be relevant to the submitted work.

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The corresponding author had full access to all of the data in the study and takes full responsibility for the integrity of the data and the accuracy of the data analysis.

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Appendix 1. List of partecipating centres.

Centre	Responsible
Department of Experimental, Diagnostic and Specialty Medicine, St. Orsola Malpighi Hospital, University of Bologna, Bologna	Federico Bardazzi
Department of Oncology and Neuroscience, Dermatologic Clinic, University G. D'Annunzio, Chieti	Paolo Amerio
University of Catanzaro (Italy) C/O Fondazione per la Ricerca e la Cura dei Tumori 'Tommaso Campanella' COE, Dermatology Unit, Germaneto di Catanzaro (CZ)	Fabrizio Amoruso
Marche Polytechinic University, Department of Clinical and Molecular Sciences, Dermatology Unit, Ancona	Anna Campanati
University of Modena and Reggio Emilia, Department of Dermatology, Modena	Andrea Conti
Catholic University of the Sacred Heart, Department of Dermatology, Rome	Clara De Simone
University of Verona, Department of Medicine, Section of Dermatology and Venereology, Verona	Paolo Gisondi
Department of Dermatology, Spedali Civili Brescia, Brescia University, Brescia	Giulio Gualdi
Department of Clinical Experimental Medicine, Section of Dermatology - University of Messina c/o A.O.U. "G. Martino", Messina	Claudio Guarneri
University of Bari, Dermatology Clinic, Bari	Francesco Loconsole
Department of Dermatology, San Camillo-Forlanini Hospital, Rome	Annamaria Mazzotta
AOU Policlinico-Vittorio Emanuele, PO G. Rodolico, Department of Dermatology, Catania	Maria Letizia Musumeci
University of Padova, Department of Medicine, Dermatology Unit, Padova	Stefano Piaserico
Sapienza University, Polo Pontino, A. Fiorni Terracina Hospital, UOC of Dermatology 'Daniele Innocenzi', Rome	Concetta Potenza

Appendix 2. Patient form.

Centre code:_____

Patient number:_____ Data enrolled_____

Date of birth (dd/mm/yyyy) ___/___/_____ Sex ☐ Male ☐ Female

Nationality: ☐ Italian Other_____

Educational level/qualifications:

☐ None ☐ Primary school ☐ Middle school

☐ High school diploma ☐ Degree ☐ Post-degree

Employment: ☐ Student ☐ Employed

☐ Unemployed

☐ Pensioner

Geographical area: ☐ North ☐ Centre ☐ South ☐ Major islands

Residence/home: ☐ Coastal area ☐ Inland ☐ Other

Living arrangements: ☐ Alone ☐ With family ☐ Other

Internet access: ☐ Yes ☐ No

Exposure to sun (hours/day): Spring/summer_____ Autumn/winter _____

Referral: ☐ First visit ☐ Check-up ☐ From another

Date symptoms started (dd/mm/yyyy) ___/___/_____ (indicate at least the year)

Date of diagnosis (dd/mm/yyyy) ___/___/_____ (indicate at least the year)

Other members of family with psoriasis ☐ Yes ☐ No ☐ Don't know

Psoriasis Area and Severity Index score (PASI) _____

Organ systems involved

Skin	Yes	No	Not known
Bone and joints	Yes	No	Not known
Nails	Yes	No	Not known
Hair and scalp	Yes	No	Not known
Genitals	Yes	No	Not known

Co-morbidities

Obesity	Yes	No		**Treated**	
Hypertension	Yes	No	Don't know	Yes	No
Diabetes	Yes	No	Don't know	Yes	No
Fatty liver	Yes	No	Don't know	Yes	No
Uveitis	Yes	No	Don't know	Yes	No
Cardiovascular disease	Yes	No	Don't know	Yes	No
Dyslipidaemia	Yes	No	Don't know	Yes	No
Inflammatory bowel disease	Yes	No	Don't know	Yes	No
Depression	Yes	No	Don't know	Yes	No
Alcohol abuse	Yes	No	Don't know	Yes	No
Cigarette smoking	Yes	No	Don't know	Yes	No
Others	Yes	No	Don't know	Yes	No

Number of portions of fruit consumed (per week)_____

Number of portions of veg consumed (per week) _____

Healthy diet? ☐ Yes ☐ No ☐ Don't know

Already receiving treatment for psoriasis ☐ Yes ☐ No

If yes what type of therapy: ☐ Systemic ☐ Topical ☐ Phototherapy