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INVESTIGATIVE REPORT

Living with Psoriasis: Prevalence of Shame, Anger, Worry, and Problems in Daily Activities and Social Life

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Psychosocial problems are frequent among patients with psoriasis. The aim of this study was to analyse the prevalence of some specific psychosocial issues. These were evaluated in 936 patients using the emotions and functioning scales of the Skindex-29 questionnaire. The problems most frequently experienced were: shame, anger, worry, difficulties in daily activities and social life. All problems were associated with the severity of psoriasis and with depression or anxiety. Shame, worry and annoyance were more frequent in women than in men, and shame and anger were associated with a low level of education. Impairment in work/hobbies was significantly higher in patients with palmoplantar psoriasis and those with arthropatic psoriasis. In conclusion, clinicians could gain important insights about their patients by looking at the single items of a quality of life instrument, to identify patients with high levels of emotional and social problems, in order to improve quality of care.

Key words: psoriasis; quality of life; Skindex-29; shame; anger; worry.

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Visible dermatological conditions, such as psoriasis, even when not clinically severe or during periods of remission, may have a strong psychosocial impact on patients' lives (1–4). Social stigmatization and rejection are commonly experienced by patients with psoriasis (5), with a consequent profound effect on self-confidence, self-image and sense of wellbeing (6). Moreover, in different studies, patients with psoriasis reported feelings of embarrassment and shame (7), and showed a higher state of anger, compared with healthy controls (8). These feelings all often result in changes in behaviour, such as the avoidance of public places or situations where the skin is exposed, thus reducing social life and inhibiting relationships with others. Even employment opportunities can be reduced, with negative consequences on income (9).

Evaluation of the psychosocial impact of psoriasis is usually included in the evaluation of health-related quality of life (HRQoL) of the patient. For this purpose, specific questionnaires are used, which give either an overall HRQoL score (10), or subscale scores (e.g. symptoms, emotions, and functioning scales) as in the Skindex-29 (11). However, single items are not simply "generators of information" to be used in the computation of the scale measurements. They usually derive, before the definition and validation of a questionnaire, from interviews with patients, and focus groups, and thus represent a meaningful summary of patients' experiences. Therefore, further clinically useful information can be obtained by looking at the single questions of an instrument (12, 13). In fact, in a previous paper, focused on the single items from the symptoms scale of the Skindex-29, we have shown a wide discrepancy between the clinical description of psoriasis available in prestigious textbooks of dermatology and the actual experience of the patients (14). In this study, we aimed to describe several components of the psychosocial impact of psoriasis by quantifying the frequency of severe impairment reported by patients in each single question of the emotions and functioning subscales of the Skindex-29.

MATERIALS AND METHODS

This study is part of a wide project on clinical, epidemiological, emotional and quality-of-life aspects of psoriasis, the IDI Multipurpose Psoriasis Research on Vital Experiences (IMPROVE) study. The project has been described in detail previously (15). The study population consisted of inpatients with a diagnosis of psoriasis recruited in a large dermatological hospital, at their first hospitalization for psoriasis since the date of the beginning of the study, being 18 years of age or more, and with no severe mental or other physical illness. All eligible patients who gave their written informed consent were recruited to the study.

The clinical severity of psoriasis was assessed by a dermatologist, using the Psoriasis Area and Severity Index (PASI) (16), and the Physician Global Assessment (PGA) on a five-point scale, from "very mild" to "very severe", before any medication was administered. The patient evaluated the severity of the disease using the self-administered PASI (SAPASI) (17, 18). The dermatologists also collected information on socio-demographic variables, clinical history, and other factors of clinical interest (e.g. clinical type and location of the disease, personal and family history of psoriasis and other diseases, symptoms, age of onset, duration of the disease, etc.).

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For the purpose of this study, we analysed the emotions and functioning scales of the Skindex-29 (11), a self-administered dermatological HRQoL instrument. The symptom scale has been analysed in a previous paper (14). The emotions scale includes 10 items (worry that the disease may be serious, depression, worry about having scars, shame, worry that the disease gets worse, anger, embarrassment, frustration, humiliation and annoyance), and the functioning scale includes 12 items (sleep disturbance, problems in work/hobbies, social life, tendency to stay at home, problems being close to loved ones, difficulty doing things independently, difficulty in showing affection, problems in interactions, problems with loved ones, desire to be with people, sexual life, tiredness). Patients answered the questions referring to the previous 4-week period, on a 5-point scale: "never", "rarely", "sometimes", "often", or "all the time". The Italian version, which was validated earlier in our institute, was used (19).

The 12-item version of the General Health Questionnaire (GHQ-12) (20) was used to evaluate the possible presence of minor non-psychotic psychiatric conditions, such as depression and anxiety. The GHQ-12 scores were computed collapsing adjacent responses to obtain a dichotomous scoring (0-0-1-1) and adding together the score of each question to obtain the total score (possible range 0–12). Patients scoring ≥ 4 were operationally defined as having possible non-psychotic psychiatric disorders (21).

Statistical analysis

Items of the Skindex-29 scales, with answers on a 5-point scale, were transformed in a dichotomous variable, grouping "sometimes", "often" and "all the time", and "never" with "rarely". The prevalence of each item in subgroups of the study population determined by gender, age, education, clinical type, PASI, SAPASI, age of onset, duration of the disease, and GHQ-12 was calculated. Erythrodermic, generalized, and inverse forms of psoriasis were grouped in the category "other", because of the small number of cases in each group. Classes of PASI and SAPASI scores were defined by quartiles.

Differences in the prevalence of the items observed in the levels of each clinical and sociodemographic variable were tested using χ^2 statistics. p-values < 0.05 were considered significant. Logistic regression models were tested using each of the more frequent items as the dependent variable, and gender, education, clinical type, severity, duration and GHQ-12, as the independent variables. Age and age of onset were not introduced in the models, because of collinearity with the variable "duration".

All statistical analyses were run under SPSS, version 9.0 for Windows.

RESULTS

The study was conducted on 936 patients, out of 1,721 patients with psoriasis hospitalized during the study period (269 were not contacted, 121 refused to participate, and 395 were excluded because they did not meet the inclusion criteria).

The mean age of the patients was 45.7 years. Overall PASI scores had a mean value of 8.3 and a median of 7.1, whereas the mean overall SAPASI score was 14.7 and the overall median was 12.

Fig. 1 show the prevalence of the answers to each item of the Skindex-29 emotions and functioning scale, respectively. Negative emotions were experienced sometimes, often or all the time by 37% (humiliation) up to 85% (annoyance) of patients, and functioning problems by 33% (problems with loved ones) to 69% (difficult to carry out work/hobbies) of patients. On the basis of the frequency of the items (i.e. those more frequently experienced "often" or "all the time"), except for depression, which has been described widely in patients with psoriasis (22, 23), some items were selected and further analysed.

Table SI (available from http: //www.medicaljournals.se/acta/content/?doi=10.2340/00015555-1273) reports the percentage of patients reporting shame, worry, anger and annoyance, "sometimes", "often" or "all the time", for different variables. All 4 emotions were experienced more often by women than by men, and by patients with probable depression and anxiety (GHQ cases) compared with GHQ non-cases. A trend with age was not observed. Shame and anger were more frequent in patients with a low level of education. Such emotions were particularly frequent in patients with arthropathic psoriasis and those with palmoplantar psoriasis (except for shame). A correlation with severity was observed for anger and annoyance. Shame was correlated with severity, as measured by PASI and SAPASI. Shame and anger were also more frequent in patients with a longer disease duration, while a later age of onset was associated with worry.

The functioning problems (Table SII; available from http://www.medicaljournals.se/acta/content/?doi=10.2340/00015555-1273) more often reported were "the disease makes it difficult to do work/hobbies", "it affects social life", and "it affects interactions". All three problems were reported significantly more often by GHQ cases compared with non-cases. Problems in work/hobbies were more frequently reported by women, by patients aged 40–49 years, by patients with palmoplantar and arthropathic psoriasis, and with high clinical severity. Social life was particularly impaired in patients aged ≥ 30 years, in patients with arthropathic psoriasis, with severe psoriasis, with a later age of onset, and a longer duration of the disease. Problems in interactions with the others were associated with older age, low educational level, arthropathic psoriasis, and severity of the disease.

The results of the logistic regression models are shown in Table I. The presence of each selected item "sometimes", "often" or "all the time" was significantly associated with the severity of psoriasis and with the probable presence of depression or anxiety. Shame, worry and annoyance were more frequent in women than in men, and shame and anger were associated with a low level of education. Impairment in work/hobbies was significantly higher in patients with palmoplantar and with arthropathic psoriasis. The duration of the disease was significantly associated with shame and anger.

DISCUSSION

The high prevalence of psychosocial problems reported in this study by a large group of patients with psoriasis

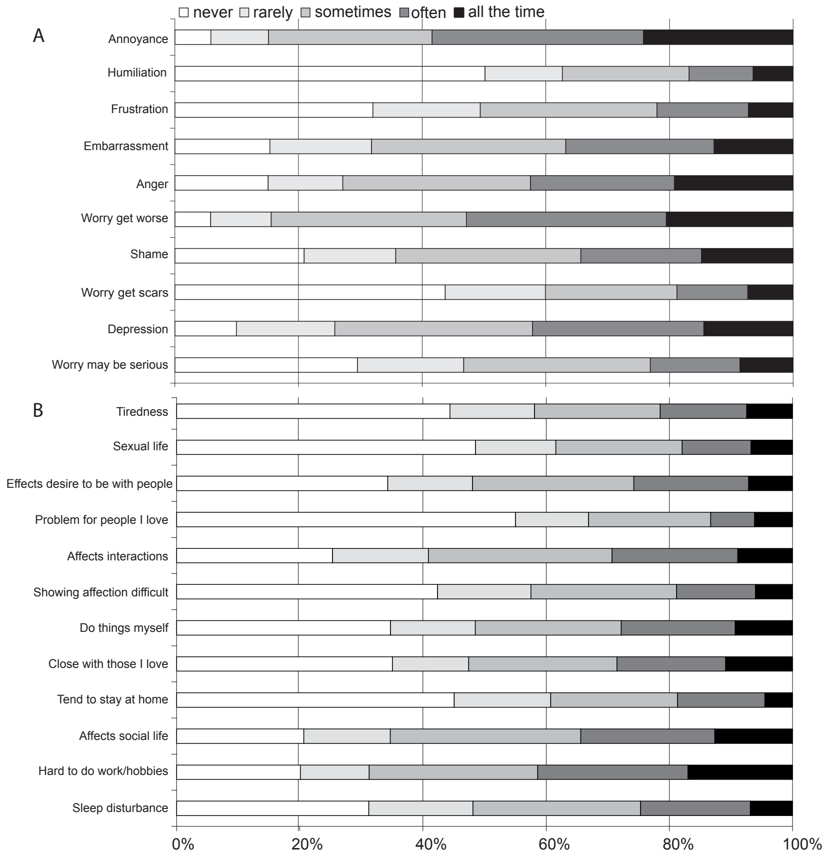

Fig. 1. Prevalence of the items of the (A) emotions scale and (B) functioning scale of Skindex-29 in 936 patients with psoriasis.

confirmed the previous results (24). The purpose of this study was to evaluate each of the main problems reported by the patients in more depth. In particular, the emotions that were more often experienced by patients were: depression, shame, worry, anger and annoyance, and the functioning problems more often reported were "the disease makes it difficult to do work/hobbies", "it affects social life", and "it affects interactions".

A frequent experience of patients with psoriasis, due to the visibility of the disease, is stigmatization (25). Stigma was defined as a biologic or social mark that sets a person off from others, is discrediting, and disrupts interactions with others (26). Among the themes at the basis of the stigma experience, shame has an important role. In the present study, shame was one of the most-often reported emotions, especially by women and by patients with a long disease duration. Feelings of shame can have a strong impact on social life, since they can result in avoidance of public places, thus reducing social opportunities, even concerning employment, and relationships (6). In particular, sexual relationships can be impaired, and problems can persist even after large clinical improvements in psoriasis (13).

In previous studies analysing single psychosocial characteristics, anger was reported by patients with psoriasis as a quite common feeling (27, 28), and more frequently than in healthy controls (8). Anger is an important trait to be analysed, since it has been observed that it is a significant risk factor for coronary artery disease (29), and it is associated with depression (30). Moreover, assertion and expression of anger is a personality trait that may adversely affect the patient's capacity to cope with stress (31). It has been observed that higher anger expression increased the probability of having early- vs. late-onset psoriasis (32). However, we did not find such association in the present study; anger was associated with a longer duration of psoriasis. It is interesting to observe the inverse association between anger and educational level, which was also observed previously (33). In addition, we observed that patients with a lower level of education experienced more shame.

Pathological worrying is an important emotional aspect of psychological well-being that is associated with psoriasis (34). It has been shown (35) that psychological distress, in the form of excessive worrying, may even have a significant and detrimental effect on treatment outcome in patients with psoriasis. In the present study, worry that psoriasis could get worse was particularly frequent in women and in patients with higher severity levels. A higher prevalence of psychological distress in women than in men has often been observed in psoriasis (36, 37), so it is not surprising that looking at specific components, such as worry, the same data are obtained.

Concerning the social aspects, it is commonly recognized that the stigma associated with psoriasis affects multiple facets of a patient's life, including relationships, social activities, and work (6, 38). In the present study, these aspects were associated with the severity of the disease, and they were more frequent in arthropathic psoriasis. As expected, problems in work were also more frequent in patients with palmoplantar psoriasis. In fact, psoriasis may have a negative impact on work, both for psychological and clinical reasons. Wu et al. (39) showed that psoriasis patients were more likely to have missed work for health-related reasons, had significantly more health-related work productivity impairment, more overall work impairment, and more impairment in activity other than work than did non-psoriasis patients. This can have financial consequences and may limit lifetime earning potential (9).

Although we have reported many associations between these psychosocial aspects and several relevant socio-demographic and clinical variables, such asso-

Table I. *Odds ratios (OR) and confidence intervals from the logistic regression models (bold characters indicate significant OR)*

Independent variables	Shame	Worry	Anger	Annoyance	Work	Social life	Interactions
Gender							
Men (ref.)	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Women	**1.6 (1.1–2.2)**	**1.8 (1.2–2.8)**	1.2 (0.8–1.7)	**1.9 (1.2–3.0)**	1.1 (0.8–1.6)	1.0 (0.7–1.4)	1.0 (0.7–1.3)
Education							
University (ref.)	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Primary school	**2.1 (1.0–4.3)**	1.1 (0.4–2.8)	**2.6 (1.2–5.6)**	1.2 (0.4–3.3)	1.7 (0.8–3.6)	1.4 (0.7–2.9)	1.6 (0.8–3.3)
Junior high school	1.4 (0.8–2.7)	1.1 (0.5–2.6)	**2.2 (1.21–4.1)**	0.8 (0.3–1.8)	1.4 (0.7–2.6)	1.0 (0.5–1.9)	1.2 (0.7–2.3)
High school	1.1 (0.6–2.0)	0.8 (0.3–1.7)	1.5 (0.8–2.8)	1.0 (0.4–2.4)	1.2 (0.7–2.3)	1.0 (0.5–1.8)	1.0 (0.5–1.8)
Clinical type							
Other (ref.)	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Palmoplantar	0.7 (0.3–1.8)	2.8 (0.8–10.0)	1.8 (0.6–5.1)	2.2 (0.6–8.7)	**8.1 (2.4–27.6)**	2.5 (0.9–6.5)	2.1 (0.8–5.5)
Pustular	0.6 (0.2–1.9)	1.6 (0.4–6.9)	1.8 (0.5–6.9)	0.7 (0.2–3.2)	0.8 (0.3–2.7)	1.1 (0.4–3.7)	1.0 (0.3–3.2)
Guttate	1.1 (0.4–2.7)	0.7 (0.2–2.0)	0.8 (0.3–1.9)	0.4 (0.1–1.4)	0.8 (0.3–1.8)	1.2 (0.5–2.8)	1.0 (0.4–2.5)
Plaque localized	1.5 (0.6–3.6)	1.9 (0.7–5.5)	1.2 (0.5–3.0)	2.0 (0.6–6.3)	1.6 (0.7–3.9)	1.9 (0.8–4.5)	1.7 (0.7–4.1)
Plaque generalized	1.6 (0.7–3.6)	1.3 (0.5–3.5)	1.1 (0.5–2.6)	1.0 (0.3–3.0)	1.3 (0.6–2.9)	2.2 (0.9–4.9)	**2.3 (1.0–5.3)**
Arthropathic	2.4 (0.9–6.4)	1.8 (0.5–6.2)	1.1 (0.4–3.1)	1.5 (0.4–6.4)	**3.0 (1.0–9.0)**	**3.2 (1.2–8.7)**	2.2 (0.8–5.8)
PGA							
Very mild (ref.)	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Mild	1.6 (0.9–2.7)	**2.9(1.6–5.4)**	1.5 (0.9–2.6)	1.7 (0.9–3.1)	1.7 (0.9–2.8)	1.6 (0.9–2.6)	1.1 (0.7–1.9)
Moderate	**1.9 (1.1–3.4)**	**2.0 (1.1–3.9)**	**2.5 (1.4–4.5)**	**2.6 (1.3–5.3)**	**2.1 (1.2–3.8)**	**1.8 (1.0–3.2)**	1.3 (0.7–2.2)
Severe/very severe	1.3 (0.7–2.3)	**3.2 (1.6–6.5)**	**2.1 (1.1–3.8)**	**3.5 (1.7–7.5)**	**2.8 (1.5–5.3)**	**2.9 (1.6–5.3)**	**1.9 (1.1–3.5)**
Duration							
<4 years (ref.)	1.0	1.0	1.0	1.0	1.0	1.0	1.0
≥4 years	**1.4 (1.0–2.0)**	1.4 (0.9–2.1)	**1.7 (1.2–2.4)**	1.2 (0.8–1.9)	0.9 (0.6–1.3)	1.3 (0.9–1.5)	1.0 (0.8–1.5)
GHQ-12							
Non cases (ref.)	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Cases	**4.0 (2.9–5.5)**	**3.0 (1.9–4.6)**	**3.5 (2.5–4.9)**	**4.4 (2.7–7.1)**	**3.9 (2.8–5.5)**	**4.2 (3.0–5.8)**	**4.9 (3.6–6.7)**
Improvement of predicted cases	5.9	0.0	1.6	0.8	3.2	4.2	9.9
Model χ^2, $p<0.001$	142, 15 df	76, 15 df	108, 15 df	105, 1 5df	139, 15 df	134, 15 df	155, 15 df
Nagelkerke R square	0.20	0.14	0.17	0.20	0.20	0.20	0.22

ciations should not be interpreted as causal, given the cross-sectional nature of the study. It would be interesting to assess the possible influence of such traits on the outcome of treatment, using an appropriate prospective study design.

A further limitation of our study may derive from the fact that hospitalized patients have been recruited. Even if in Italy a wide range of clinical presentations of psoriasis are hospitalized, for diagnostic procedures and treatments that may not be widely available (e.g. psoralen plus ultraviolet A (PUVA)), especially in the more disadvantaged central and southern regions, it is possible that our estimates are biased upwards, and caution should be used in generalizing our results to different settings. However, given the standardized procedures and methods used, the IMPROVE study has good internal validity (13–15), so that the identification of subgroups of patients particularly burdened by specific psychosocial problems related to the disease, should be valid.

However, the dermatologists should be aware that anger, shame, and worry, and social problems carry with themselves a higher probability of clinically relevant issues. Therefore, they should pay particular attention to these psychosocial aspects in the evaluation of psoriasis patients, who may require particular clinical attention, and may benefit from adjunctive psychological interventions before and during treatment.

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