

CLINICAL REPORT

Significance of the Stigmatization Experience of Psoriasis Patients: A 1-Year Follow-up of the Illness and its Psychosocial Consequences in Men and Women

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Feelings of stigmatization are an important somatopsychic consequence of psoriasis, affecting the quality of life. It is thus relevant to supplement reliable statements about the detailed changes of stigmatization experience and psoriasis over time. In this study we compared the Psoriasis Area and Severity Index (PASI), the 'self-administered PASI' (SPASI) and the 'Questionnaire on Experience with Skin Complaints' of 166 psoriasis patients (64 women, 102 men) in a 1-year follow-up to assess the relation between these factors over time. The results suggest a more pronounced feeling of discrimination in women with no significant somatic differences between gender at the first measurement. In a prospective evaluation we found a clear proportion of 'discordant' courses of these parameters, mainly in women, indicating a contradictory relation of somatic improvement or deterioration vs subjective experience with skin complaints. All in all, these results show a moderate but significant relevance of skin state for feeling of stigmatization over time only in men, thus suggesting a considerable influence of other psychic variables, probably coping skills, especially in women. *Key words: psoriasis; stigmatization; stress; rehabilitation psychology; sex-specific effects; coping; PASI.*

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A somatopsychic view is a central object of psychological research in patients with psoriasis, primarily focusing on coping (1–5), disability (5–8), quality of life (9–18), or feelings of stigmatization (2, 7, 12, 17–22). Skin lesions relevant to interactions (e.g. of the genital region) (2, 22) may cause feelings of stigmatization; stigma experience may cause stress (1, 19, 23, 24) and correlate negatively with the quality of life (17, 18).

Corresponding to the influence of sex on stigmatization experience the results are contradictory, with no influence of gender (22) and higher levels of

discrimination feeling in women (19). Richards et al. (7) revealed a significantly greater PASI (Psoriasis Area and Severity Index) in men in their sample; in contrast to this, women scored higher with regard to disability (Psoriasis Disability Index, PDI), stigmatization (Feelings of Stigmatization-Questionnaire, cf. ref. 19), anxiety and depression (Hospital Anxiety and Depression Scale; HADS). Multiple regression analysis indicated a significant influence only of gender, stigmatization experience and HADS depression, but not of PASI and HADS anxiety on psoriasis-related disability.

Thus, stigmatization feelings remain one main topic of psychological research tradition in psoriasis. However, until now patients' illness perceptions and coping predicting functional status in psoriasis have been studied in a 1-year follow-up but not the influence of somatic severity on stigmatization. Stigmatization experience in psoriasis patients can be differentiated using the 'Questionnaire on Experience with Skin Complaints' (QES), originally based on the 'Feelings of Stigmatization Questionnaire' by Ginsburg & Link (19). The 38-item QES consists of 6 factors (22): 'Interference of skin symptoms and self-esteem' describes feelings of being worthless, alone or unclean. The dimension 'Outward appearance and situation-caused retreat' contains items comprising experience with lack of physical attractiveness or sexual desirability in the context of the skin disease; other items cover special ways of dressing or avoiding public situations. The items of the factor 'Rejection and devaluation' describe anticipated or perceived reactions of others. 'Composure' includes calmness and confidence in a satisfactory life in spite of the skin disease. The scale 'Concealment' comprises tendencies toward hiding the diagnosis and keeping the disease a secret. The items of the factor 'Experienced refusal' include the feelings of stigmatization in very concrete situations, such as shopping or using public transport. The results of our earlier studies suggested that, as predictors of stigmatization experiences, the affection of problematic regions (lower abdomen and genitals) was significantly involved in determining all the stress dimensions of the QES in psoriatic and atopic dermatitis patients (2, 22).

However, statements about psychic factors and psoriasis taken from cross-sectional studies allow only limited conclusions, even if they consider somatic severity.

The follow-up presented here was initiated to confirm the following hypotheses: 1) Showing comparable somatic severity, the feeling of discrimination in women is significantly more intensive than in men at the first measurement; 2) The degree of stigmatization experience and skin symptoms correlates modestly but significantly in women and in men at both measurements; 3) The degree of stigmatization experience (QES) varies – with respect to gender – in a 1-year follow-up design dependent on the *courses* of the skin symptoms measured by PASI or SPASI (self-administered PASI). Thus, the study includes a prospective evaluation of the relation between the courses of these somatic and psychic parameters between the two measurements.

PATIENTS AND METHODS

The data describe the 1-year follow-up of 347 psoriasis inpatients (201 men and 146 women) at the Department of Dermatology of the Bad Bentheim Rehabilitation Hospital, who took part in the study after giving their informed consent. The inpatients were examined in their first week after admission and a dermatologist confirmed the diagnosis (T1). An outpatient follow-up was gathered after 1 year (T2, mean=12.5±0.9 months). At the follow-up assessment the sample consisted of 166 patients (102 men, 64 women). Reasons for non-responders not to participate at T2 may be related to the patients now participating in outpatient treatment at their place of residence and their distance from the rehabilitation clinic.

We used the PASI (25) for the examination of the inpatients and, in the follow-up, the SPASI (26, 27) as well as the PASI in a T2 subgroup. The QES was used with both measures. The QES is a fully-standardized self-rating instrument focusing on the feelings of stigmatization and coping with the stigma experience in patients with different chronic skin diseases; the highest value corresponds to an extremely marked stigmatization feeling in combination without a minimal composure (2). The SPASI used at T2 is a self-rating questionnaire for psoriasis patients based on the PASI and with the same gradation and highly correlating with the PASI (26, 27). Furthermore, in a subsample ($n=60$) at T2 the correlation between PASI and SPASI was proved to be high with a correlation coefficient of 0.81 ($p<0.001$), demonstrating the good homogeneity of the results of both versions of these screening questionnaires.

In addition, we assessed the subjective rating of the general extent of skin involvement (5=maximum), the degree of burden by the skin disease (5=very marked) and the state of health (5=in good health) by a single question, as well as basic sociodemographic data (sex, age, partnership, and membership of a self-help group) by relevant items of the questionnaire.

Statistics

To ensure that the results are not an artefact from a selection process we conducted a missing analysis by comparing the characteristics of the sample with completely returned questionnaires at T1 and T2 ($n=166$) and the characteristics of the patients who are excluded from analyses with univariate

ANOVA (mean scores) and χ^2 tests (categorical variables of the frequencies). These statistical methods were also used to compare social and anamnestic characteristics of men and women at T1, i.e. examining the first hypothesis. In addition, a multiple regression analysis of these parameters on the QES total score was conducted. The second hypothesis focusing on the relation of stigmatization experience and skin symptoms at both measurements was studied by determining their correlation coefficients. The third hypothesis evaluating the relation of the courses of these somatic and psychic parameters between T1 and T2 (i.e. the differences T2 – T1 of the QES and (S)PASI values) was tested using paired t-tests and χ^2 tests again. All data were analysed by the statistical package 'R' for Windows (28).

RESULTS

The comparison of all socio-demographic and illness-related characteristics of the remaining sample studied and those of the patients who are excluded from analyses ($n=181$) revealed no significant difference in sex, age, state of health, partnership, age at beginning, duration since first period, subjective (general assessment) or objective (PASI) rating of extent of skin involvement at T1 (data not shown). This gives a strong hint that the members of this group are missing at random (29). Thus, the conclusion is justified that there was no relevant systematic bias with regard to the sample with completely returned questionnaires at T1 and T2 concerning the somatic, psychic or socio-demographic data (29).

Significant gender differences were found for QES, partnership (trend) and working status, but not for age, duration since first period, general state of health, skin involvement, burden by the skin disease, PASI or membership of a self-help group (Table I). With regard to the social and anamnestic information the sample can be seen as representative of patients hospitalized for rehabilitation including about 60% men and 40% women, but not for the true prevalence of this skin disease, being about 1:1. In addition, the *mean* stigmatization experience is not too high. However, with about 5% of men and 11% of women in this sample the rate of members of a self-help group is high compared with about one-thousandth in Germany.

In contrast to the significant difference between women and men in the central parameter, 'stigmatization feeling' (QES total value) at measurement T1 (ANOVA, $p<0.01$), the difference between the PASI in women and men was not significant (ANOVA, $p=0.35$). Thus, the first hypothesis could be confirmed and therefore, men and women were subsequently studied separately.

The exploration of the influence of sociodemographic and illness parameters on the feelings of stigmatization at T1 with a multiple regression analysis of these parameters on the QES total score supported these results: only the variables 'burden of skin disease'

Table I. Comparison of men and women in the sample included in the analyses at T1 (non-miss, univariate ANOVAs and χ^2 tests; Df 1)

| Parameter | Men (n=102) (mean \pm SD) | Women (n=64) (mean \pm SD) | F-value | P (F) |
|--|--------------------------------|---------------------------------|----------|---------|
| Age (years) | 45.9 \pm 11.3 | 45.6 \pm 14.4 | 0.02 | 0.89 |
| State of health (range 1–5) | 2.9 \pm 0.9 | 3.1 \pm 0.9 | 2.59 | 0.11 |
| Age at beginning (years) | 27.3 \pm 12.1 | 25.6 \pm 13.8 | 0.71 | 0.40 |
| Duration since first period (years) | 18.8 \pm 11.4 | 20.3 \pm 12.8 | 0.61 | 0.44 |
| Extent of skin involvement (range 0–5) | 3.00 \pm 1.2 | 3.1 \pm 1.1 | 0.39 | 0.53 |
| Burden by the disease (range 0–5) | 2.4 \pm 1.4 | 2.7 \pm 1.4 | 1.34 | 0.25 |
| QES (range –5 to 25) | 3.6 \pm 3.8 | 5.5 \pm 4.9 | 7.76 | 0.01 |
| PASI (range 0–72) | 9.5 \pm 6.9 | 8.5 \pm 6.4 | 0.87 | 0.35 |
| | n (%) | n (%) | χ^2 | p-value |
| Partnership | 83 (81.4%) | 44 (68.8%) | 2.82 | 0.09 |
| Membership in a self-help group | 5 (4.9%) | 7 (10.9%) | 1.33 | 0.25 |
| Working | 76 (74.5%) | 32 (50.0%) | 9.34 | <0.001 |

PASI, Psoriasis Area Severity Index; QES, Questionnaire on Experience with Skin Complaints.

Table II. Correlations between Psoriasis Area Severity Index (PASI), self-administered PASI (SPASI) and Questionnaire on Experience with Skin Complaints (QES) at different time points (T1 and T2)

| | SPASI (T2) | QES (T1) | QES (T2) |
|---------------------|------------|----------|----------|
| <i>Men (n=102)</i> | | | |
| PASI (T1) | 0.60** | 0.33** | 0.27** |
| SPASI (T2) | | 0.22* | 0.34** |
| QES (T1) | | | 0.62** |
| <i>Women (n=64)</i> | | | |
| PASI (T1) | 0.64** | 0.31* | 0.31* |
| SPASI (T2) | | 0.34** | 0.42** |
| QES (T1) | | | 0.82** |

* $p < 0.05$; ** $p < 0.01$.

($p < 0.01$), PASI ($p < 0.01$) and gender ($p < 0.01$) had a significant influence on the stigmatization experience.

The second hypothesis focuses on the correlation between the absolute values of QES and PASI/SPASI, separately for men and women. They correlated modestly but significantly in men and women at both measurements, with correlation coefficients around 0.30 (Table II).

Finally, we compared the changes of QES with the changes of the PASI/SPASI between the first measurement (T1) and the follow-up (T2) prospectively, taking gender of the patients into account. We used χ^2 statistics comparing the four possible combinations of either improvement (T2 – T1: difference < 0) or deterioration (T2 – T1: difference ≥ 0) concerning (S)PASI and QES score (Table III). The mean (S)PASI was significantly reduced at the follow-up T2 in men (9.5 \pm 6.9 vs 7.4 \pm 5.2, $p < 0.001$), but not in women (8.5 \pm 6.4 vs 7.4 \pm 7.6, $p = 0.12$). In contrast, the QES total value was only significantly lower at the follow-up T2 in women (5.5 \pm 4.9 vs 4.5 \pm 5.0, $p < 0.05$). Although the comparison of the (S)PASI and QES means at T1 and T2 partly revealed no significant results, the developments of these

Table III. Comparison of the changes of Questionnaire on Experience with Skin Complaints (QES) with the changes of the Psoriasis Area Severity Index (PASI/SPASI) between T1 and T2 considering the patients' gender (χ^2 test)

| | QES | | |
|------------------------------------|----------------------------|--------------------------|------|
| | Deterioration ^a | Improvement ^b | P |
| <i>Men (n=102)</i> | | | |
| (S)PASI Deterioration ^a | 24 | 13 | 0.03 |
| Improvement ^b | 26 | 39 | |
| <i>Women (n=63)</i> | | | |
| (S)PASI Deterioration ^a | 9 | 17 | 0.99 |
| Improvement ^b | 14 | 23 | |

^aT2 – T1: difference ≥ 0 , ^bT2 – T1: difference < 0 .

parameters include the possibility of deterioration and improvement for subgroups of men and women. Thus, we studied these courses and found only in men, but not in women, a significant relation between the change patterns of the QES and the (S)PASI, suggesting that only in men the somatic course of the psoriasis has a significant influence on their stigmatization experience (Table III). It is noteworthy that, in addition to the expected coincidence of a better skin and a better adaptation and vice versa, we also found a considerable proportion, mainly in women, of a deteriorated skin, but a better adaptation ($n = 17$, $\approx 27\%$) or a better skin but a worse adaptation ($n = 14$, $\approx 22\%$).

DISCUSSION

Psychic stress including actual experiences of discrimination by others (20, 21) and anticipation of the potential for stigmatization can be a long-lasting strain factor in patients with psoriasis. Psoriasis patients partly avoid situations which could be accompanied by a feeling of stigmatization (e.g. choosing an occupation which is combined with public business or going

swimming). Stigmatization experience (QES) correlates negatively with Dermatology Life Quality Index (DLQI) (2, 18), although the two questionnaires focus on different aspects, with the QES referring to special psychosocial aspects in contrast to the DLQI, which asks more globally about limitations in the different areas of life.

Some methodological limitations on the interpretation of these results should be noted. First, the questionnaires used for this study share the limitation of being self-reports: QES at the first measurement T1, and both QES and SPASI at the second measurement T2. However, SPASI and the QES used in this study are now well-established instruments (2, 22, 30, 31). Second, with the PASI and the SPASI two different instruments have been used to measure somatic symptoms. But a high correlation of PASI and SPASI could be shown in several studies (26, 27, 30, 31) and also in this study at T2. Third, due to non-responders the sample studied here is reduced at follow-up. However, there is obviously no relevant systematic bias. Thus, we think that these methodological limitations are balanced by the methodological and conceptual strengths of this follow-up study with its large sample size, which enables us to study the relation between courses of stigma experience and skin symptoms in men and women.

The data of the study presented here first indicate that at T1 only the stigmatization experience (QES) was significantly higher in women than in men, whereas skin affection (PASI) was comparable (cf. Table I). One year after treatment in a rehabilitation clinic, somatic severity of the psoriasis significantly decreased in men and feelings of stigmatization in women. Second, we found a significant but only low correlation between the feelings of stigmatization and the (S)PASI in men and women (Table II) at T1 and T2. In the sense of explained variance, e.g. of stigmatization experience by the skin state, this is fairly small (around 10%), underlining the relevance of other, probably *psychic* factors for feelings of discrimination in psoriasis patients. Third, our hypothesis concerning the influence of the somatic psoriasis severity on the *course* of feelings of stigmatization could be confirmed only in men. All in all, the impact of the skin state on the psychic adaptation, as measured for example by the QES, must be regarded as being far from 'strong' or deterministic. In addition to concordant improvements or deteriorations of these parameters, we found a considerable proportion of 'discordant' courses, in women (about 50%) more than in men (about 40%). These subgroups underline the influence of important intervening variables, which may be assumed to be responsible for different coping abilities. The quadrant of cases, for example, who reported a non-improved skin but a better adaptation (men, $n=13$; women $n=17$), may have experienced a successful habituation to or coping with the disease,

probably as an effect of the rehabilitation. The other 'discordant' subgroup with a better skin but a non-improved adaptation (men, $n=26$; women, $n=14$) might have had unrealistic expectations of the treatment. By this, in addition to the influence of the somatic skin state, our results give strong support to the importance of coping-related variables in women more than in men, which need to be traced in further prospective research. All in all, these results correspond to earlier findings of cross-sectional studies: in women in most of the studies a stronger impact of different skin diseases including psoriasis on the DLQI (8, 10, 11) or health-related quality of life (13) as well as stigmatization experience (7, 19) was found. In summary, the findings of these different previous studies and this examination empirically support the particular need for clinicians to focus on psychosomatic aspects of psoriasis, especially in women, and to consider gender aspects in future quality of life and psychodermatological studies.

The DLQI and the stigmatization feeling (QES) in psoriasis patients were highly correlated, with the absolute values of these two psychological constructs being not different from a comparable group of patients with atopic dermatitis (18). However, in another study (17) psoriasis patients reported a significantly higher stigmatization experience than a matched comparison group of patients with different skin problems, whereas the general quality of life (World Health Organization WHOQOL-Bref) and somatic severity of the disease of the two groups were reported to be comparable. Only in psoriasis patients, but not in the comparable group, a stigmatization feeling showed a mediating effect of the somatic disease severity on general quality of life; however, the somatic severity of different skin diseases is difficult to compare.

In the context of psychodermatological comprehension, it is relevant that psoriasis can often be treated not only at one of the somatic manifestations but also by focusing on its psychological impacts (32–35) or if there is a comorbidity of a mental or a behavioural disorder like a social anxiety (36). The psychological consequences include the bodily suffering of severely affected patients including the management of visible regions, coping with a subjectively all-consuming disease, and social vulnerability (37). The detailed examination of changes of the different dimensions of stigmatization experience by different psychosocial interventions could be a relevant topic for further psychodermatological studies.

In addition, it can be concluded that the dermatologist could improve quality of life for a considerable amount of psoriasis patients in practice by carefully screening different dimensions of stigmatization feelings like lowered self-esteem, situation-caused retreat, experiences of being rejected or refused, and concealment of the skin symptoms, considering these as subjectively

justified perceptions of the consequences of living with this disease. Especially in women, dealing with this theme may also be relevant if the 'objective' somatic symptoms are not very marked, if no actual experiences of discrimination by others are reported by the concerned individuals, and even if there is a reluctance of patients to report their psychological distress, with consequent greater focus on physical symptoms than on psychic aspects like stigmatization (38).

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