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# Validity Study for the Stigmatization Experience in Atopic Dermatitis and Psoriatic Patients

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A central experience of patients with atopic dermatitis and psoriasis is the feeling of stigmatization. This can be estimated by the "Questionnaire on Experience with Skin Complaints" (QES), based on the "Feelings of Stigmatization Questionnaire" by Ginsburg & Link. This study was designed to evaluate the psychometric properties of the QES, especially the validity of this questionnaire, and to supply more information about the stigmatization experiences of patients with atopic dermatitis and psoriasis. Three groups of patients were analysed: 76 with atopic dermatitis, 81 and 217 with psoriasis, respectively. The comparison of subgroups with different affected regions revealed that the genital region is especially relevant for the stigmatization experience in these patients. In addition, the feeling of stigmatization (estimated by the QES) is relatively independent of the different dimensions of the "Trier Scales of Coping with Diseases", except for the depressive coping style "Rumination" measuring a high amount of inner concern with the afflicting disease. It can be concluded that the QES is a valid and reliable instrument for examining the stigmatization experience of patients with atopic dermatitis and psoriasis. *Key words:* stigma; psychological examination; coping.

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Atopic dermatitis (AD) and psoriasis are chronic skin diseases that cause a lot of psychosocial stress. Psychic stress, primarily as "daily hassles" (1, 2) and feelings of stigmatization (3–8) can be severe strain factors and have an adverse effect on life quality (9). Stangier et al. (10) described "Stigmatization" in one scale of their coping questionnaire specific to skin diseases. Using the "Questionnaire on Experience with Skin Complaints" (QES), based on the "Feelings of Stigmatization Questionnaire" of Ginsburg & Link (4), the stigma experience of patients with skin diseases can be differentiated. In an initial study (3) we presented the meaning of the 5 QES dimensions for psoriatic patients: "Interference of skin symptoms and self-esteem" (in the following abbreviated to "Self-esteem") comprises feelings of being worthless, alone or unclean. The dimension "Outer appearance and situation-caused retreat" ("Retreat") contains items describing experiences with lacking physical attractiveness or sexual desirability in the context of the skin disease; other items require special ways of dressing or avoiding public situations. The items of the factor "Rejection and devalua-

tion" ("Rejection") comprise anticipated or perceived reactions of others. "Composure" describes calmness and confidence in a satisfactory life in spite of the skin disease. The scale "Concealment" includes tendencies of hiding the diagnosis and keeping the disease a secret.

The present study was designed to supply more information about the stigmatization experience of patients with AD and psoriasis and the psychometric properties of the QES, especially the different types of validity of this questionnaire (see Table I).

## MATERIALS AND METHODS

### *Patients and methods*

We examined a group of 76 patients with AD who fulfilled the criteria of Hanifin & Rajka (11), a group of 81 patients with psoriasis at the Department of Dermatology, Hannover Medical School (Pso 1) and another group of 217 patients with psoriasis at the Department of Dermatology of the Bad Bentheim Hospital (Pso 2); part of the last group has been studied before (3). The 34-item QES based on the instrument of Ginsburg & Link (4) has been described elsewhere (3). The QES is a fully standardized self-rating instrument that focuses on the feelings of stigmatization of patients with different skin diseases and the coping with the stigma experience. Basic sociodemographic data were gathered for all 3 groups. The objective extent of the skin disease was estimated for the Pso 1 group by the Psoriasis Area and Severity Index "PASI" (12) and for the AD group by the Severity Scoring of Atopic Dermatitis "SCORAD" (13), respectively.

The "concurrent validity" of the QES was studied in 2 steps. First, the degree of the burden by the skin disease was selected as the characteristic that should be highly correlated with the scores of the QES measuring feelings of stigmatization. In addition, we analysed 2 more features that were assumed to be less strongly covarying with stigmatization: the duration of the disease and the determination of the objective severity of the skin symptoms at present. The degree of burden by the skin disease was assessed by a single question, formulated as follows "How marked is your suffering from the skin disease at the moment?".

In a second step the degree of feeling stigmatized depending on the localization of the current skin state was examined as a further hint for "concurrent validity". For that purpose, information on the current skin symptoms was categorized into 3 classes, representing psychologically related localizations: "invisible" (arms, upper part of the body, legs, feet), "visible" (scalp, face, neck, hands) and "sensitive" (lower abdomen, genitals) regions of the body. The extent of the stigmatization experience was rated by the patients on a 6-point Likert scale from "does not apply at all" (–3) to "highly applicable" (+3); i.e. a high value corresponds to a high feeling of stigmatization (scales Self-esteem, Retreat, Rejection and Concealment) and a high Composure, conversely.

For all 3 groups of patients (AD, Pso 1 and 2) the 3 following hypotheses were formulated:

Table I. Types of validity of the "Questionnaire on Experience with Skin Complaints" (QES)

Type	Subtype	Definition	Operationalization in the present study	Interpretation
Criterion validity	Concurrent validity	Ability of an instrument (e.g. QES) to distinguish individuals who differ in their present state	1. Interrelation between the degree of the subjective burden by the 2 skin diseases, their duration, their objective severity and the stigmatization experience (QES)  2. Comparison of subgroups of individuals with different degrees of sensitivity and visibility of the 2 skin diseases	1. The differently marked correlations are compared  2. The results are more powerful if one is able to show that one can differentiate between 2 groups that are rather similar, e.g. having 1 disease and different affections of the body regions
Construct validity	Convergent validity	Theoretically deduced comparisons of the measure of the same construct (e.g. psychosocial consequences of a disease=somatopsychic aspects) with 2 instruments	The results of the measure of somatopsychic aspects for atopic dermatitis and psoriatic patients are compared: stigmatization (QES) and coping, estimated by the "Trier Scales of Coping with Diseases" TSK by Klauer & Filipp (14)	Two measures of the same construct (somatopsychic aspects) with defined dimensions of the QES and of the TSK yield similar results
	Discriminant validity			Measure with (defined dimensions) of the instrument to be tested (QES) is independent of the measure with (defined dimensions) of another instrument (TSK)
Content validity	–	An ideal valid test of a construct (e.g. stigmatization) would include a representative set of items or subscales featuring all available characteristics of this construct	It is considered if the scales of the QES represent the available characteristics of the subject social stigma deduced from the comprehensive work about it by Goffman (16) and Jones et al. (17), especially regarding skin diseases	

1. The affection of the "visible" regions compared with the "invisible" ones is associated with a significantly higher feeling of stigmatization (Self-esteem, Retreat and Rejection) and a lower Composure.
2. The affection of the "sensitive" regions compared with the "invisible" ones is associated with a significantly higher stigmatization experience and a lower level of Composure.
3. The affection of the "sensitive" regions compared with the "visible" ones is associated with a significantly higher feeling of stigmatization and a less marked Composure.

In order to evaluate the QES for "construct validity", the questionnaire was given in conjunction with the "Trier Scales of Coping with Diseases" TSK by Klauer & Filipp (14), based on the transactional coping-model by Lazarus & Launier (15). The TSK comprises 5 subscales, labelled "Rumination", "Social Support", "Defence of Threats", "Seeking Information" and "Support from Religion". Convergent validity was assumed between the scale "Rumination" and the "pathologic" scales of the QES (Self-esteem, Retreat, Rejection and Concealment). The constructs of the QES that measure affliction and the scale Composure, which describes a kind of "passive" coping, were in the sense of discriminant validity assumed to be independent of the 4 remaining scales of the TSK focusing on different kinds of active coping with the disease.

All data have been analysed using the statistics program system SPSS for Windows.

## RESULTS

### *Characteristics of the sample*

The patients in the 3 groups (i.e. AD, Pso 1 and Pso 2) were significantly different concerning sex distribution and mean age, but with a comparable range ( $p < 0.05$ ;  $\chi^2$  and 2-tailed  $t$ -test, respectively). The 3 groups of patients were considerably different regarding the duration of the skin diseases ( $p < 0.05$ ; 2-tailed  $t$ -test). These differences can be explained in part by the age difference (Table II).

### *Concurrent validity—the QES and the severity and location of the disease*

The major results of the concurrent validity evaluation are presented in Tables III and IV. Here, the concurrent validity testing was carried out first by studying the relationships between the 5 QES scales and characteristics of the skin disease (burden by the skin disease, severity and duration) in the 3 groups (Table III). As assumed, the "burden by the skin disease" was strongly and significantly correlated with the QES scales. The correlations between the other 2 features

Table II. Sociodemographic and illness-related data of the 3 groups of patients

Diagnosis	Atopic dermatitis	Psoriasis 1	Psoriasis 2
<i>n</i>	76	81	217
Age (years)	32.1 (±12.1)	42.3 (±15.5)	47.1 (±13.5)
Age range (years)	17–70	16–77	17–75
Sex			
M	32 (42%)	37 (46%)	152 (70%)
F	44 (58%)	44 (54%)	65 (30%)
Duration since first period (years)	17.0 (±13.6)	13.9 (±12.2)	18.1 (±13.1)
Working	51 (67%)	51 (63%)	148 (68%)

severity and duration of the skin disease and the 5 QES dimensions for all 3 groups of patients were much weaker, mostly not revealing significant interrelations. The results with the Composure scale were different.

Table IV shows the importance of the affection of different body regions for the feeling of stigmatization measured by the QES-scores (hypotheses 1–3) as a second aspect of concurrent validity. For the Pso 2 group the second and the third hypotheses (cf. for these the expected stronger significant interrelations in Table IV that are marked by a shaded background) could be confirmed. That is, patients with the “sensitive” regions affected felt significantly more stigmatized than those with the “invisible” and the “visible” regions affected. However, unexpectedly, the patients with the “visible”

Table III. Concurrent validity of the QES 1–interrelations between QES-scores and characteristics of the diseases. Expected stronger significant interrelations shown in bold

	Severity		Burden by the skin disease			Duration		
	AD <sup>b</sup>	Pso 1 <sup>a</sup>	AD	Pso 1	Pso 2	AD	Pso 1	Pso 2
Self-esteem	0.36**	0.20	<b>0.57**</b>	<b>0.46**</b>	<b>0.49**</b>	0.21	0.29**	0.15
Retreat	0.42**	0.14	<b>0.53**</b>	<b>0.52**</b>	<b>0.43**</b>	0.27*	0.38**	0.19
Rejection	–0.08	0.12	<b>0.26*</b>	<b>0.35**</b>	<b>0.34**</b>	0.10	0.28*	0.09
Composure	–0.33*	0.11	–0.15*	0.05	–0.30**	0.09	0.02	0.03
Concealment	0.15	0.15	<b>0.25*</b>	<b>0.42**</b>	<b>0.48**</b>	0.14	0.20	0.26*

\**p* < 0.05; \*\* *p* < 0.01.

<sup>a</sup>PASI Score (11); <sup>b</sup>SCORAD Index (12).

AD = 76 atopic dermatitis patients of the Department of Dermatology, Hannover Medical School; Pso 1 = 76 psoriatic patients of the Department of Dermatology, Hannover Medical School; Pso 2 = 217 psoriatic patients of the Department of Dermatology of the Bad Bentheim Hospital, Bad Bentheim, Germany.

Table IV. Concurrent validity of the QES 2–the meaning of different localizations for the QES-scores. Expected stronger significant interrelations shown with shaded background

AD ( <i>n</i> = 76)	SR <sup>a</sup> ( <i>n</i> = 9)	VR <sup>b</sup> ( <i>n</i> = 42)	IR <sup>c</sup> ( <i>n</i> = 25)	ANOVA	Contrasts		
					VR/IR	IR/SR	VR/SR
Self-esteem	0.06	–1.38	–0.90	*	*		*
Retreat	1.23	–0.11	0.17	*			*
Rejection	–0.21	–1.27	–0.94	*			*
Composure	–0.25	0.13	–0.48				
Concealment	–0.98	–1.88	–1.62				
Pso 1 ( <i>n</i> = 81)	SR <sup>a</sup> ( <i>n</i> = 18)	VR <sup>b</sup> ( <i>n</i> = 19)	IR <sup>c</sup> ( <i>n</i> = 44)	ANOVA	Contrasts		
					VR/IR	IR/SR	VR/SR
Self-esteem	–0.40	–1.51	–0.69	+			
Retreat	0.82	–0.10	0.60				
Rejection	–0.72	–1.68	–1.01	+			
Composure	–0.69	0.24	0.08	*			
Concealment	–1.33	–1.93	–1.65				
Pso 2 ( <i>n</i> = 217)	SR <sup>a</sup> ( <i>n</i> = 35)	VR <sup>b</sup> ( <i>n</i> = 105)	IR <sup>c</sup> ( <i>n</i> = 77)	ANOVA	Contrasts		
					VR/IR	IR/SR	VR/SR
Self-esteem	0.06	–1.38	–0.90	***		*	*
Retreat	1.23	–0.11	0.17	***		*	*
Rejection	–0.21	–1.27	–0.94	***		*	*
Composure	–0.25	–0.48	0.13	*	*		
Concealment	–0.98	–1.88	–1.62	***		*	*

<sup>+</sup>*p* < .1; \**p* < .05; \*\**p* < .01; \*\*\**p* < .001; <sup>a</sup>“sensitive” regions = SR: lower abdomen, genitals; <sup>b</sup>“visible” regions = VR: scalp, face, neck, hands; <sup>c</sup>“invisible” regions = IR: arms, upper part of the body, legs, feet; mean scale values.

Table V. Convergent and discriminant validity of the QES as indicated by interrelations of the QES and the TSK; AD ( $n=76$ ), Pso 1 ( $n=81$ ), Pso 2 ( $n=217$ ). Expected stronger significant interrelations in the sense of convergent validity are shown in **bold**

	Rumination		Social support		Defence against threatening		Search for information		Support by religion	
	AD	Pso 1	AD	Pso 1	AD	Pso 1	AD	Pso 1	AD	Pso 1
Self-esteem	<b>0.57**</b>	<b>0.46**</b>	0.19	0.10	0.01	0.07	0.30**	0.23**	0.40**	0.21
Retreat	<b>0.55**</b>	<b>0.50**</b>	0.16	0.16	0.15	0.10	0.22	0.22	0.25*	0.27*
Rejection	<b>0.32**</b>	<b>0.45**</b>	0.15	0.16	0.03	0.08	0.28**	0.12	0.30**	0.32**
Composure	-0.17	0.04	0.22	0.04	0.18	0.09	0.02	0.05	0.05	0.02
Concealment	<b>0.48**</b>	<b>0.41**</b>	0.06	0.11	0.13	0.12	0.24*	0.14	0.37**	0.39**

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

QES=Questionnaire on Experience with Skin Complaints; TSK=Trier Scales of Coping with Diseases (14).

regions affected had a significantly higher Composure than those with the “invisible” regions affected. Besides, the patients with the “sensitive” regions affected hid their symptoms significantly more than those with the “invisible” and even the “visible” regions affected. In the AD group the third hypothesis could be largely confirmed: patients with “sensitive” regions affected had a significantly higher feeling of stigmatization (Self-esteem, Retreat and Rejection) than the group with “visible” regions affected. However, unexpectedly, patients with the “invisible” regions affected had lower Self-esteem than those with the “visible” regions affected.

#### Construct validity—the QES and measure of coping (TSK)

As can be seen in Table V, the inter-scale correlations of the QES and TSK that we assumed would indicate convergent validity (in bold type), were substantially higher in AD and psoriasis than the interrelations that we assumed to be independent, i.e. indicating discriminant validity (not bold type). With respect to convergent validity it had been assumed that only the “pathologic” scales of the QES (Self-esteem, Retreat, Rejection and Concealment) show significant interrelations with the dimension “Rumination” of the TSK, which is “related” in the sense of a similar construct. This could be confirmed. However, in contrast to our assumption, the scale “Support from religion” of the TSK also yielded a notable number of significant correlations with the QES dimensions, but this TSK scale, unexpectedly, showed no correlation with the QES scale Composure. However, the level of the interrelations of this coping scale “Support from religion” with the QES dimensions Self-esteem, Retreat, Rejection and Concealment was lower than that of the TSK scale “Rumination” (cf. Table V).

#### DISCUSSION

Concerning the “concurrent validity” of the “Questionnaire on Experience with Skin Complaints” QES (cf. Table I) the results of the study presented here primarily stress the clinical relevance of the stigmatization experience relatively independent of objective somatic factors: duration of the disease, the PASI in psoriasis and, with certain restrictions, the SCORAD in atopic dermatitis (see Table III). The higher correlations between some scales of the QES and the SCORAD scores might be traced back to the partially different construction

compared with the PASI, including self-report data, such as itching and sleep loss. The different results concerning the dimension Composure may be explained by the slightly exceptional position of this scale, measuring the counterpart of “stigmatization”, i.e. the coping with stigma feelings and thus being scaled in reverse.

All in all, our hypotheses concerning the importance of different localizations for the QES scores (second aspect of concurrent validity) could be confirmed (see Table IV). On the other hand, the results were more or less pronounced according to the sample. This may in part be due to the somewhat different character of the samples (see Table II) concerning age, duration and the locality of treatment. We assume that the less pronounced results with the Pso 1 sample stem from the fact that these patients are younger and are treated in a hospital, rather than in a rehabilitation unit as were the patients in the Pso 2 group. Thus, the attitudes towards the disease may be influenced more intensely by hope and the fact that we are dealing with a “subchronic” feeling of stigmatization. This possible explanation does not impair the interpretation that, after a lasting arrangement with the psoriasis, the results concerning more or less important regions of affection can probably be generalized. Interestingly, the data also suggest comparable relevance of the “sensitive” sites being affected in atopic dermatitis.

In the context of the “construct validity” of the QES (see Table I) we emphasize that “stigmatization” hardly correlates with coping factors, except for the depression-related scale “Rumination”. The lack of strong (negative) correlations between one of the stigmatization scales and the coping dimension “Social support” is remarkable. This means that, at least in this sample, stigmatization experience shows a relative independence of social integration. Summarizing the feeling of stigmatization seems to vary rather independently of the coping style (Table V).

Regarding “content validity” (cf. Table I), stigmatization as a sociological field of interest was thoroughly examined by Goffman (16) and subsequently by Jones et al. (17). Goffman named the spoiled “social”, “personal” and “ego identity” (the last including the ‘felt’ identity and the advice the stigmatized is given regarding the stigma and its management) as constituent features for the feeling of stigmatization. Jones et al. (17) added the following 6 characteristic dimensions for stigma in general: “Concealability”; “Course”; the “Disruptiveness” in communication of the “normal” with the

“stigmatized”, in this context the skin patient; “Aesthetic qualities”; “Origin” and “Peril” focusing on the dangers posed by stigmatized persons. These features can be regarded as sufficiently well represented by the resulting 5 scales of the QES Self-esteem, Retreat, Rejection, Composure and Concealment. One can conclude that the utilization of the 5-dimensional QES (3) (a German version with 6 dimensions has been presented recently (18)) can be helpful to differentiate the feeling of stigmatization, which is the important precondition for adequately dealing with this experience.

The findings of this study are to a certain extent in accordance with the results of Stangier et al. (10), who found patients with psoriasis experienced significantly more “Stigmatization” in the Marburg Atopic Dermatitis Questionnaire than did patients with atopic dermatitis. In contrast, a significantly smaller “Amount of burden” and “General emotional burden” were described in psoriatic than in patients with AD in the study of Stangier et al. (10); however, the stigmatization experience was also clearly observable in patients with atopic dermatitis.

In practical clinical work with patients with AD and psoriasis, stigmatization should be regarded as possibly the most afflicting feature of these diseases and as a secondary source of stress. Recent research identified psychological stress as possibly responsible for maintaining and exacerbating these skin diseases by psychoneuroimmunological mechanisms (19–21). If the feeling of stigmatization is the most burdensome secondary symptom for an individual, specific help in the form of psychosocial intervention should be provided in addition to dermatological therapy.

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