



# Stigma experiences and perceived stigma in patients with first-episode schizophrenia in the course of 1 year after their first in-patient treatment

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## Abstract

Patients with schizophrenia suffer from stigma and discrimination due to their illness. Yet it is not well examined how experiences of stigma and discrimination express at the early illness stage and how they develop subsequently. Therefore, clinical and psycho-social correlates of stigma experiences and perceived stigma are analyzed in patients with first-episode schizophrenia over the course of 1 year after their first in-patient treatment. Questionnaire data assessed within the multi-centre-RCT “First-Episode Study” of the German Research Network on Schizophrenia were analyzed. Patients with first-episode schizophrenia were assessed 8 weeks after their first in-patient treatment (post-acute assessment) and 1 year later.  $N=48$  (post-acute) and  $N=24$  (1-year follow-up) patients provided questionnaire data appropriate for analyses, with  $N=12$  dyads. These data included burden due to stigma experiences (B-STE), perceived stigma (PDDQ), clinical (PANSS, CDSS, CGI, GAF, SAS) and psycho-social factors (LQLP, FSNK-self-esteem, KK-Scale). Cross-lag-correlation models showed a causal relation between stigma experiences (post-acute) and reduced self-esteem after 1 year. Multiple regression models revealed different models for experienced and perceived stigma. Factors associated with higher stigma experiences were older age, worse clinical global impression, better social adjustment, lower self-esteem, and the belief that illness is not driven by chance or fate. The different associations between psycho-social factors and stigma experiences and perceived stigma demonstrate the complexity of this inter-relationship. The results have practical implications for psycho-educational and other therapeutic interventions addressing stigma coping. Since the sample was small and selective, replication studies are needed.

**Keywords** Stigma · First-episode schizophrenia · Perceived stigma · Stigma experiences · Long-term study

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## Introduction

Despite the manifold endeavors to fight the stigma of mental illness and its consequences, including interventions addressing the public, specific target groups, and people with mental illness, and reaching from grass-roots level activities to international anti-stigma campaigns [1–7], people with mental illness still suffer from public stigma and discrimination [8–11]. Evidence indicates that in recent years public stigma has not diminished, rather it has increased [12] while public perception of stigma has decreased [13]. Against this background, further development and ongoing implementation of anti-stigma interventions have a high priority in the field of mental health.

While many anti-stigma interventions aim to achieve more realistic and less stigmatizing attitudes (or behavior) towards people with mental illness, another interventional approach addresses the individuals' reactions to the stigma [1]. These reactions influence the treatment process, particularly the patients' treatment motivation, and are in opposition to realistic perceptions of impairment, which are a pre-requisite for successful treatment and rehabilitation [14]. They are summarized by the term personal stigma [15], comprising personal experiences of stigma and discrimination (enacted stigma) as well as perceptions about how people with mental illness are being stigmatized in their society (perceived stigma) [4, 16, 17], and, furthermore, self-stigmatizing attitudes and beliefs [18, 19].

Psycho-social consequences of the stigma are various and include suffering from impaired empowerment and social inclusion [5, 20, 21], loss of quality of life, social isolation, impaired self-esteem and self-efficacy [22]. A large proportion of first episode psychosis patients is affected: up to 50% of them do experience discrimination, while about a third is limited in their access to important live opportunities [23]. In addition to that, consequences of the mental illness stigma are not restricted to those suffering from mental illness, but also affect caregivers (courtesy stigma, cf. [24]). As Chen et al. [25] report, internalized stigma in caregivers is associated with higher levels of stress, anxiety and depression.

Two strategies have been proposed to support people with mental illness in coping with the consequences of stigma [26]: first, modifying the patients' dysfunctional stigma-related beliefs and attitudes (reducing the "self-stigma", cf. [19]), and second, enhancing the patients' skills by promoting empowerment, increasing self-esteem, and help-seeking behavior. Recently, therapeutic interventions (usually referring to methods of cognitive behavioral therapy) have been developed to support patients with mental illness in coping with stigma [26–29].

Nevertheless, it has been argued that many interventions targeting mental health patients lack a sound methodological and theoretical foundation [26], and more detailed knowledge of the patients' experiences, views and reactions to stigma is needed. In particular, little is known about the specific consequences of stigma experiences in the course of schizophrenia and how these evolve during the course of illness [1, 30, 31].

The stigma of schizophrenia is mainly characterized by the stereotypes of dangerousness, unpredictability, and a poor prognosis [32]. It hampers intentions to seek professional help or treatment, as shown for first-episode patients and undiagnosed persons with a high risk of developing a psychosis [24, 33, 34]. It also contributes to the prolongation of the duration of untreated psychosis and thus to a worse prognosis [35]. Finally, having feelings of being threatened by stigma is suggested as a risk factor for transition into schizophrenia among young people at risk of psychosis [36].

Only few further studies examined long-term effects of stigma in the early stages of psychosis. Ho et al. [31] found that patients with a higher symptom burden during their first episode of psychosis showed increased values of self-stigma after 3 years. Additionally, higher perceived stigma and the cognitive appraisal of stigma as a stressor were identified as predictors of negative attitudes towards psychotherapy after 1 year [37]. In the present study, possible long-term effects of stigma experiences are examined in a sample of patients with first-episode schizophrenia over the course of 1 year. Previous cross-sectional analyses of the presented data have shown that burden due to stigma experiences is associated with lower quality of life, lower self-esteem and higher perceived stigma after the first in-patient treatment [38]. In the present study, possible long-term associations of perceived stigma and burden due to stigma experiences are being analyzed. Symptom severity, functioning, social abilities, and psycho-social variables as quality of life, self-esteem, and illness concepts are analyzed as possibly correlating variables.

## Methods

The presented data were assessed within the multi-centre randomized clinical trial "First-Episode Study" at 13 participating psychiatric university hospitals (Bonn, Cologne, Düsseldorf, Munich, Tübingen, Berlin, Essen, Jena, Mannheim, Göttingen, Mainz, Halle, and Aachen) conducted under the umbrella of the German Research Network on Schizophrenia (GRNS) and funded by the German Ministry of Education and Research. Research rationale and methods of the main study are described in detail in [39, 40]. The study complied with the ethical principles of good clinical practice (GCP) and the declaration of Helsinki. Ethical approvals

were obtained by the responsible ethical committees of all study centers.

## Sample

$N = 173$  patients with first-episode acute schizophrenia (ICD-10 F20.0-F20.9) were included in the study. A detailed overview of the patient flow is given elsewhere in a CONSORT diagram [39]. “First episode” was defined as having no previous in-patient treatment because of schizophrenia. Consequently, previous outpatient treatment or untreated psychotic episodes did not count as exclusion criteria. The first data assessment of the main study took place after the participants had experienced 8 weeks of initial in-patient treatment. Participants were then asked to fill in a questionnaire about stigma experiences as an add-on after completing the main assessments, which was done by  $N = 48$  patients (response rate 27.7%). A second assessment after 12 months yielded questionnaires from  $N = 24$  patients (25.0% of 96 participants of the long-term study with  $N = 12$  measurement pairs). The rather low response rates are due to the conduction of the survey as an add-on to the pharmacological and psychological RCTs with very comprehensive assessments as primary objectives; the topic of stigma was seen of minor relevance for the clinical treatment course at that time. An analysis of possible selection biases showed that persons who participated in the stigma assessments were significantly older and showed better compliance [41] as well as better social adjustment [42]. Within the group of persons who participated at the stigma assessments, persons who participated in the 1-year follow-up were older and more compliant than those persons who participated only in the post-acute assessment. None of the further assessed variables differentiated between these two groups.

## Instruments

The clinical assessment included the following variables and scales: age and gender; illness severity: Positive and Negative Syndrome Scale (PANSS [43]); clinical global impression (CGI [44]); depression symptoms: Calgary Depression Scale for Schizophrenia (CDSS [45]); functioning: Global Assessment of Functioning Scale (GAF [46]); social abilities: Social Adjustment Scale II (SAS [42]). Self-ratings were used for the assessment of the following psycho-social factors: quality of life: Lancashire Quality of Life Profile (LQLP [47]); self-esteem: Frankfurt Self-Concept Scales subscale self-esteem (FSKN [48]); and illness concepts (KK-Scale [49]). Cronbach’s alpha values were calculated for the post-acute sample ( $N = 48$ ): PANSS 0.94, CDSS 0.80, LQLP 0.85, and FSKN-self-esteem 0.92. The KK-Scale comprises seven dimensions of illness concepts: trust in medication (alpha = 0.79), trust in the treating physician (0.73), negative

treatment expectations (0.82), guilt (0.82), chance control (0.54), susceptibility (0.62), and idiosyncratic beliefs (0.52).

Furthermore, two aspects of personal stigma were assessed with self-rating scales: perceived stigma and burden due to stigma experiences. Perceived stigma was assessed with the Perceived Devaluation and Discrimination Questionnaire (PDDQ [17]). The questionnaire comprises 12 Likert-scaled (1—strongly disagree to 5—strongly agree) items with statements about perceived social acceptance or, conversely, about stigmatization and discrimination of persons with mental illness, for example: “Most people think less of a person who has been in a mental hospital”. The PDDQ was adapted regarding the scale format (original: 1—strongly disagree to 6—strongly agree) and by adding an item to provide German gender-specific phrasings for the item about dating a friend (“Most young women would be reluctant to date a man who has been hospitalized for a serious mental disorder”). The scaling format of 1–5 was chosen to provide consistent scaling formats with other items of the assessment which are not subject of the present analysis. A sum score was calculated (range 12–72; high values represent high perceived stigma). It is corrected for the changed scaling by multiplying the raw score with a correction factor of 1.2 and for the additional item by weighting both gender-specific items about dating a friend with 0.5 to provide a sum score which is comparable to other studies using the PDDQ. Reliability analysis yielded a good Cronbach’s alpha for the adapted scale (alpha = 0.882). Stigma experiences were assessed with the scale “Burden due to Stigma Experiences B-STE” [38]. The B-STE scale (Cronbach’s alpha = 0.796) assesses general experiences of stigma and discrimination, for example: “I have been treated as being less competent by other people, when they recognized that I have a mental illness”. The five items are Likert-scaled (1—never to 5—very often); a scale sum score was calculated with a range from 5 (lowest burden of stigma experiences) to 25 (highest burden).

## Statistical analysis

Comparisons between post-acute and 1-year follow-up assessments were calculated with the Fisher’s exact test and the  $t$  test for independent samples. These procedures were chosen due to the small number of patients who completed both measurements ( $N = 12$ ). In general, nonparametric statistical procedures have been used for any statistical tests with groups smaller than  $N = 20$  [50]. A multiple regression model (backward elimination algorithm) was calculated to analyze the cross-sectional multivariate relationships between the assessed variables and the B-STE scale at post-acute assessment. The same procedure was applied for the PDDQ. For the rather low case numbers ( $N = 48$ ) for the post-acute assessment, the explorative backward elimination

algorithm was applied to achieve sufficient test power without excluding possible predictor variables at the same time. By doing so, inter-correlating factors as the clinical factors PANSS, CGI, CDSS, and GAF could be included into the initial models. Cross-lag-correlation models were calculated to reveal possible causal relationships between the stigma scales PDDQ and B-STE with selected variables over the course of 1 year.

## Results

### Sample characteristics

Sample characteristics are shown for both the post-acute and 1-year follow-up assessments in Table 1. All variables describing symptom severity and illness-related impairment (CGI, PANSS, CDSS, GAF, SAS) showed a significant improvement after 1 year ( $t$  tests for independent samples CGI:  $t=3.690$ ;  $df=59.1$ ;  $p<0.001$ ; PANSS:  $t=3.190$ ;  $df=69,6$ ;  $p=0.002$ ; CDSS:  $t=2.609$ ;  $df=67.8$ ;  $p=0.011$ ; GAF:  $t=-3.033$ ;  $df=70$ ;  $p=0.003$ ; SAS:  $t=2.948$ ;  $df=65.3$ ;  $p=0.004$ ), whereas self-esteem, quality of life, all illness concept subscales, and both experienced and perceived stigma remained unchanged [ $t$  tests for independent samples ( $df=70$ ) FSKN-self-esteem:  $t=0.893$ ;  $p=0.375$ ; LQLP:  $t=-0.915$ ;  $p=0.364$ ; KK-Medic:  $t=-0.681$ ;  $p=0.609$ , KK-Physician:  $t=-1.434$ ;  $p=0.156$ , KK-Negat:  $t=0.240$ ;  $p=0.811$ , KK-Guilt:  $t=0.996$ ;  $p=0.322$ , KK-Chance:  $t=0.882$ ;  $p=0.381$ , KK-Suscept:  $-0.704$ ;  $p=0.484$ , KK-Idiosync:  $t=0.018$ ;  $p=0.985$ ; B-STE:  $t=-0.646$ ;  $df=70$ ;  $p=0.521$ ; PDDQ:  $t=-0.529$ ;  $df=70$ ;  $p=0.598$ ]. Regarding age and gender, participants of the 1-year follow-up assessment were at average 5.2 years older (at the time of study inclusion) than participants of the post-acute assessment ( $t$  test for independent samples  $t=-2.063$ ;  $df=70$ ;  $p=0.043$ ). The samples' gender compositions showed no significant differences between both assessments (Fisher exact test  $p=0.454$ ).

### Multiple regression analyses

Two multiple regression models were computed: for each stigma variable as dependent variable (stigma experiences B-STE and perceived stigma PDDQ) at post-acute assessment. All regression models included the same predictor variable set comprising age at post-acute assessment, gender, CGI, PANSS, CDSS, GAF, SAS, LQLP, FSKN-self-esteem, and the KK-subcales. Compliance was not included in the regression analyses because the distributional characteristics were insufficient (most cases showed best compliance). However, no bivariate associations were found between compliance and both stigma variables. Additionally,

**Table 1** Sample characteristics at post-acute and 1-year follow-up assessment

Variable <sup>a</sup>	Post-acute	1-year-f-up
	<i>n</i> (%)	<i>n</i> (%)
Total	48 (100)	24 (100)
Gender <sup>b</sup>		
Female	22 (45.8)	14 (58.3)
Male	26 (54.2)	10 (41.7)
	Mean (SD)	Mean (SD)
Age (at post-acute, years) <sup>c</sup>	32.0 (10.079)	37.2 (9.770)
CGI <sup>d</sup>	3.6 (1.142)	2.7 (0.859)
PANSS <sup>e</sup>	50.7 (18.046)	40.3 (9.648)
CDSS <sup>c</sup>	2.7 (3.095)	1.2 (1.834)
GAF <sup>d</sup>	63.3 (14.187)	73.4 (11.560)
SAS <sup>d</sup>	3.7 (1.223)	3.0 (0.790)
LQLP <sup>e</sup>	4.6 (0.838)	4.8 (0.993)
FSKN (self-esteem) <sup>e</sup>	28.2 (9.878)	26.1 (9.045)
KK-Medic <sup>e</sup>	14.6 (3.446)	15.2 (3.574)
KK-Physician <sup>e</sup>	11.3 (2.891)	12.3 (2.665)
KK-Negat <sup>e</sup>	7.4 (3.837)	7.2 (4.732)
KK-Guilt <sup>5</sup>	4.1 (2.760)	3.4 (2.253)
KK-Chance <sup>e</sup>	8.1 (3.257)	7.4 (3.196)
KK-Suscept <sup>e</sup>	6.4 (2.614)	6.9 (2.014)
KK-Idiosync <sup>e</sup>	7.6 (2.623)	7.6 (2.742)
PDDQ <sup>e</sup>	35.0 (8.997)	36.2 (9.944)
B-STE <sup>e</sup>	11.7 (4.166)	12.4 (4.800)

<sup>a</sup>Ranges and polarities: CGI (Clinical Global Impressions Scale) 1–7; 7: high illness severity, PANSS (Positive and Negative Syndrome Scale) 30–210; 210: high illness severity, CDSS (Calgary Depression Rating Scale for Schizophrenia) 0–27; 27: high illness severity, GAF (Global Assessment of Functioning) 1–100; 100: normal functioning, SAS (Social Adjustment Scale II) 1–7; 7: poor adjustment, LQLP (Lancashire Quality of Life Profile) 1–7; 7: high quality of life, FSKN-self-esteem (Frankfurt Self-Concept Scales subscale self-esteem) 10–60; 60: low self-esteem, KK (Illness Concept Scale) subscales: Medic (0–20; 20: high trust in medication), Physician (0–16; 16: high trust in physician), Negat (0–20; 20: negative treatment expectations), Guilt (0–12; 12: strong feelings of guilt), Chance (0–20; 20: high belief in chance), Suscept (0–12; 12: high feelings of susceptibility), Idiosync (0–16; 16: refusing attitude towards medication), PDDQ (Perceived Devaluation-Discrimination Questionnaire) 12–72; 72: high perceived stigma, B-STE (Burden due to Stigma Experiences Questionnaire) 5–25; 25: high burden due to stigma experiences

<sup>b</sup>Fisher exact test n.s. ( $p=0.454$ )

<sup>c</sup> $t$  Test for independent samples  $p<0.05$

<sup>d</sup> $t$  Test for independent samples  $p<0.01$

<sup>e</sup> $t$  Test for independent samples n.s.

intervention status [defined as medication (Risperidon vs. Haloperidol vs. no medication) × psychotherapy (yes vs. no)] was not included, yielding no bivariate associations with both stigma variables. Its inclusion as a categorical variable in the regression analyses would have had exceedingly

**Table 2** Multiple regression models for stigma experiences and perceived stigma at post-acute assessment

Model <sup>a,b</sup>	Predictor variables	Std.-beta	<i>p</i>
Stigma experiences	Age at post-acute	0.370	0.005
	CGI	0.385	0.013
	CDSS	−0.282	0.074
	SAS	−0.237	0.081
	FSKN-self-esteem	0.543	0.001
	KK-Chance	−0.282	0.033
Perceived stigma (PDDQ)	Age at post-acute	0.244	0.076
	KK-Suscept	0.341	0.015

<sup>a</sup>Models were calculated using backward elimination algorithm with the following variable set: age at post-acute assessment, gender, *CGI* Clinical Global Impressions Scale, *PANSS* Positive and Negative Syndrome Scale, *CDSS* Calgary Depression Rating Scale for Schizophrenia, *GAF* Global Assessment of Functioning, *SAS* Social Adjustment Scale II, *LQLP* Lancashire Quality of Life Profile, *FSKN* Frankfurt Self-Concept Scales subscale self-esteem, *KK* Illness Concept Scales subscales

<sup>b</sup>Model summaries: stigma experiences: *N*=48; *R*<sup>2</sup>(corrected): 0.366; *F*=5.530; *p*<0.001; perceived stigma: *N*=48; *R*<sup>2</sup>(corrected): 0.152; *F*=5.219; *p*=0.009

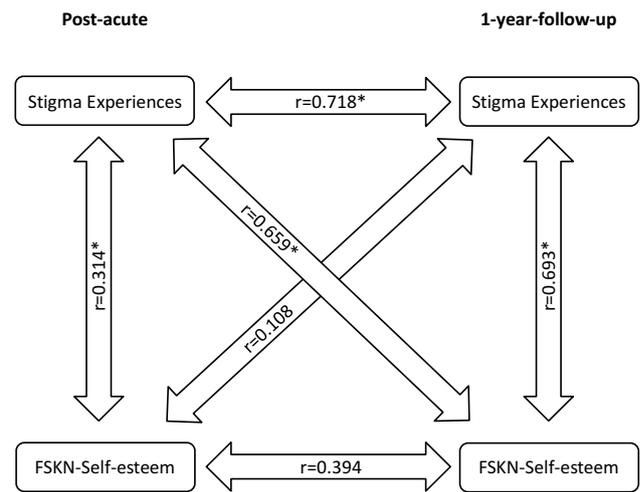
decreased the test power. The resulting regression models are shown in Table 2.

Concerning the resulting predictor patterns, the regression models vary between both stigma variables. The regression model for B-STE revealed the significant predictor variables age, CGI, CDSS, SAS, FSNK-self-esteem, and KK-Chance. It is noteworthy that the direction of the association of social adjustment (SAS) within the regression model means that a better social adjustment is related to a higher burden of stigma experiences. Regarding the predictor KK-Chance, the opinion that the illness happened by chance is associated with a lower burden of stigma experiences within the regression model.

The regression model for perceived stigma explains less variance (15.2%) than the model for burden of stigma experiences (36.6%) and includes fewer remaining predictor variables (age and KK-Susceptibility). Higher values of perceived stigma are associated with the belief that the illness is a threat for oneself.

**Cross-lag-correlation models**

Cross-lag-correlation models were computed to identify possible causal relationships between the stigma variables stigma experiences and perceived stigma with selected clinical and psycho-social variables. Variables were included in the analysis if they were significant predictors within the multiple regression models and had significant Pearson



**Fig. 1** Cross-lag-correlation model stigma experiences—FSKN-self-esteem. Synchronous correlations at post-acute and at 1-year follow-up: Pearson correlation (*N*=48/*N*=24). Auto-correlations and cross-correlations post-acute × 1-year follow-up: Spearman’s Rho (*N*=12). Stigma experiences (post-acute) × FSKN-self-esteem (post-acute): *p*=0.030. Stigma experiences (1-year follow-up) × FSKN-self-esteem (1-year follow-up): *p*<0.001. Stigma experiences (post-acute) × stigma experiences (1-year follow-up): *p*=0.009. Stigma experiences (post-acute) × FSKN-self-esteem (1-year follow-up): *p*=0.020

correlations with stigma experiences or perceived stigma at the 1-year follow-up. For B-STE, separate cross-lag models were computed with CGI, SAS, and FSKN-self-esteem. For PDDQ, no variable met the criteria to compute a cross-lag model. A causal relationship between two variables is supported by a cross-lag-correlation model with two consecutive assessments, if the following conditions apply [51]: the cross-correlation of the first variable at first assessment with the second variable at second assessment is higher than the cross-correlation of the second variable at first assessment with the first variable at second assessment. Furthermore, the correlation between both variables at the second assessment should be significant and higher than the correlation between both variables at the first assessment. Such a pattern indicates a causal relationship between the two variables, in so far that changes in the first variable lead to changes in the second variable.

The cross-lag models for B-STE with CGI and SAS did not show such a correlation pattern. The cross-lag model for B-STE with FSKN-self-esteem is shown in Fig. 1. It shows a correlation pattern supporting a causal relation in terms of higher stigma experiences at first assessment causing lower self-esteem 1 year later: the correlation between stigma experiences (post-acute) and FSKN-self-esteem (1-year follow-up) is higher than the correlation of FSKN-self-esteem (post-acute) with stigma experiences (1-year follow-up) (Spearman’s Rho=0.659; *p*=0.020 vs.

Spearman's  $Rho = 0.108$ ;  $p = 0.739$ ). Furthermore, the correlation between stigma experiences and FSKN-self-esteem is higher at 1-year follow-up ( $r = 0.693$ ;  $p < 0.001$ ) than at post-acute assessment ( $r = 0.314$ ;  $p = 0.030$ ).

## Discussion

In this study, stigma experiences and perceived stigma of patients with first-episode schizophrenia are examined over the course of 1 year after receiving their first in-patient treatment. Regarding perceived stigma, the values of the present study are comparable to those reported by Link [52] (in terms of item-scaled mean values: 2.7–2.8 (Link et al.) vs. 2.9 at post-acute to 3.0 at 1-year follow-up). Regarding burden due to stigma experiences, comparative values for the B-STE scale do not yet exist. Generally, the comparability of the results with those of other studies (e.g., [10, 11, 23, 53–55]) is limited due to different assessment methods concerning instruments, questioning (personal interview, telephone interview, postal survey) and sampling (definition of mental illness: diagnosis of schizophrenia or no diagnosis but service utilization; stages of illness: first episode or unspecified). Nevertheless, undoubtedly the burden of stigma is high for people with mental illness in general: about 90% of them report some kind of stigma or discrimination experience in practically all domains of daily living [53, 54]. The authors of a recent study with first-episode psychosis patients (using face-to-face interviews about stigma experiences and perceived stigma) concluded that specific approaches are needed to enhance patients' self-esteem early in the course of the illness [23]. The results of the present analysis support this view of self-esteem as an important factor in the development of stigma-related burden during the early course of illness.

### Changes between post-acute and 1-year follow-up

The sample shows pronounced differences between both assessments regarding the clinical variables: symptom severity (PANSS, CDSS, and CGI), global functioning (GAF), and social adjustment (SAS) all improved significantly at the 1-year follow-up. Taking clinical global impression (CGI) as indicator, average illness severity changed from a light to moderate degree to a subthreshold to light degree after 1 year. This development reflects the clinical improvement of patients with first-episode schizophrenia who (as completers of the First-Episode-Study) received treatment continuously over 1 year. It disproves the negative stereotype that people with schizophrenia will “never recover” or clinically improve [32]. In contrast to the positive clinical improvement, no significant changes were found for both stigma scales (burden due to stigma experiences and perceived

stigma)—as well as for quality of life, self-esteem and illness concepts after 1 year. A similar pattern of improved mental illness, and unchanged perceived and experienced stigma over time, has been reported by Link et al. [52] for male patients with dual diagnoses (mental illness and alcohol abuse), concluding that although the stigma is related to illness course, it is not merely part of the symptoms, or psychopathology. More general, this observation is in line with the finding that health beliefs are independent of illness severity in patients with schizophrenia [56].

### Associations between stigma scales and psycho-social variables

The finding that a high burden due to stigma experiences is associated with a reduced clinical state (CGI) and reduced self-esteem (FSKN) is in line with other studies [19, 52]. An unexpected finding is that both depressiveness (CDSS) and social adjustment (SAS) show reverse associations with burden due to stigma experiences: according to the regression model, high burden due to stigma is associated with low depressiveness and a better social adjustment. This finding indicates that there might be a subgroup of patients with a high illness burden, but being rather well socially integrated at the same time. These patients might suffer from stigma experiences more severely and thus could be a specific target group for interventions addressing stigma coping. The finding is also in line with the stigma concept of Link and Phelan [57], assuming that potential status loss is a defining consequence of the stigma process: better socially adjusted patients may feel more intensely the threat of losing their social network due to the stigma of mental illness. Nevertheless, further studies including other diagnoses and illness stages are needed to verify this assumption.

Further significant predictor variables in the burden due to stigma experiences regression models were age (the older, the higher the burden due to stigma experiences) and illness concepts (subscale chance): the belief that one's illness has happened by chance or fate is associated with a lower burden due to stigma experiences. It seems that the beliefs that the course of illness can be influenced, and that there is a comprehensible (natural) cause for the illness, are associated with a higher burden due to stigma experiences. This alludes to the point of ascribed responsibility for the illness as potentially stigmatizing attribution [58]. Although the causal direction of these associations cannot be determined within the present study, these findings are relevant for interventions addressing stigma coping and psycho-educational interventions.

While psycho-education aims to enhance the personal resources to control the course of illness in a positive way (e.g., to prevent relapses, to cope better with negative outcomes in daily living), it contradicts the belief that

the illness and its course are purely driven by fate, even though this belief might be associated with a higher burden due to stigma experiences. This finding demonstrates the complexity of the different stigma concepts and their interrelationships.

The regression model for perceived stigma explains far less variance and includes fewer significant predictor variables than the model for burden due to stigma experiences. Perceived stigma is associated with the illness concepts subscale susceptibility which describes the perception that an illness poses a threat to oneself. This relationship reflects the role of mental illness stigma as a person's identity threat [59]. Furthermore, the perception of stigma as a harmful threat is associated with perceived low resources to cope with stigma [36]. This finding could therefore be a starting point for interventions addressing stigma coping abilities. In this regard it should also be noted, that perceived stigma can be a realistic reaction of patients to deal with concrete threats [55].

### Cross-lag-correlation models

It is difficult to provide direct evidence for causal pathways in the field of stigma research with patients with mental illness as target, since possible experimental approaches with patients (e.g., inducing stigma experiences to them) would not meet ethical standards of research with human subjects. Prospective long-term and panel studies are scarce, and only few studies about stigma-related patient interventions have been published since the 1990s, most of them with no or mixed results [26]. Nevertheless, it is obvious that patients with a first-episode psychosis undergo an adaptation process after receiving their diagnosis and initiation of professional treatment [60]. The cross-lag-correlation model is a statistical method to examine possible causal relationships in panel studies, especially in the case of a small sample where multivariate approaches are not applicable due to low test power. On this basis, a causal pathway between burden due to stigma experiences and reduced self-esteem after 1 year was substantiated. Hence, skills improving self-esteem should also be part of interventions addressing stigma coping.

### Study limitations

The following points should be noticed for interpretation: Due to the stepwise sampling procedure within the First-Episode Study, the sample is small and selective, thus the results' generalizability is limited. Test–retest reliability has not been tested for both the PDDQ [14] and the B-STE-scale. In the present sample, the B-STE-scale showed an auto-correlation of  $r=0.718$  after 1 year (PDDQ:  $r=0.680$ ; both Spearman's Rho correlations  $p<0.05$ ). Due to the low number ( $N=12$ ) of measurement pairs and the low case

number ( $N=24$ ) in the 1-year follow-up, regression analyses were calculated only for the post-acute assessment. Due to the low case number, results of the regression analysis should be interpreted only with caution; in addition, conclusions deriving from the cross-lag-correlation model about the course of illness need further verification. Additionally, changes of metric variables between post-acute and 1-year follow-up have been tested with  $t$  tests for independent samples to include  $N=48$  (post-acute) and  $N=24$  (1-year follow-up) cases into the analyses. Both instruments assessing stigma variables are self-report scales. Though compliance also might have been an important factor for the multiple regression models, it was not included into the models due to its bad distribution characteristics (most subjects showed best compliance). Since the analyzed data derive from an RCT, study arm should also have been included into the regression models. Yet this was not done due to the high number of study arms (5) and the low case numbers in each study arm in the analyzed sample (lowest number of cases in a study arm:  $N=5$ ). At least in bivariate analyses, both compliance and study arm did not show significant associations with the stigma variables. Possible effects of self-stigma [61] have not been examined because corresponding instruments (e.g., the ISMI [18]) were not available at the time the study has been conducted (first data were assessed in 2000). Study medication dose has not been included in regression analyses due to small case numbers at follow-up. However, bivariate analyses showed no relationships between medication dose and both stigma variables at both assessments. The multiple regression backward elimination algorithm bears the risk of random artifacts, since not all possible predictor variable combinations are being tested. Finally, possible reasons for stigma and discrimination, other than mental illness, have not been assessed.

### Conclusions

The results of the cross-lag-correlation models indicate that stigma experiences negatively influence self-esteem of patients with schizophrenia in the early stage of the illness. The burden due to stigma experiences is associated with an older age and a poorer clinical state but better social adjustment. It is also associated with the belief that one's illness is not driven by chance or fate. These findings should be considered in the development of interventions addressing patients' skills to cope with stigma and discrimination. Thus, psycho-educational interventions promoting the patients' ability and responsibility to cope with the illness might bear the risk of increasing feelings of being stigmatized and decreasing perception of stigma at the same time. These findings require replication and verification in further patient groups regarding diagnosis and illness stage.

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## Compliance with ethical standards

**Conflict of interest** A. Schmitt has been an honorary speaker for TAD Pharma and Roche and a member of advisory boards for Roche. On behalf of all further authors, the corresponding author states that there is no conflict of interest.

## References

- Gerlinger G, Hauser M, De Hert M, Lacluyse K, Wampers M, Correll CU (2013) Personal stigma in schizophrenia spectrum disorders: a systematic review of prevalence rates, correlates, impact and interventions. *World Psychiatry* 12:155–164
- Livingston JD, Boyd JE (2010) Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. *Soc Sci Med* 71:2150–2161
- Mestdagh A, Hansen B (2014) Stigma in patients with schizophrenia receiving community mental health care: a review of qualitative studies. *Soc Psychiatry Psychiatr Epidemiol* 49:79–87
- Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rüschi N (2012) Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatr Serv* 63:963–973
- Sartorius N, Schulze H (2005) Reducing the stigma of mental illness. A report from a global programme of the World Psychiatric Association. Cambridge University Press, Cambridge
- Gaebel W, Ahrens W, Schlamann P (2010) Konzeption und Umsetzung von Interventionen zur Entstigmatisierung seelischer Erkrankungen: Empfehlungen und Ergebnisse aus Forschung und Praxis. Aktionsbündnis Seelische Gesundheit, Berlin
- Gronholm PC, Henderson C, Deb T, Thornicroft G (2017) Interventions to reduce discrimination and stigma: the state of the art. *Soc Psychiatry Psychiatr Epidemiol* 52:249–258
- Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M, INDIGO Study Group (2009) Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet* 373(9661):408–415
- Lasalvia A, Zoppei S, Van Bortel T, Bonetto C, Cristofalo D, Wahlbeck K, Bacle SV, Van Audenhove C, van Weeghel J, Reneses B, Germanavicius A, Economou M, Lanfredi M, Ando S, Sartorius N, Lopez-Ibor JJ, Thornicroft G, ASPEN/INDIGO Study Group (2013) Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey. *Lancet* 381(9860):55–62
- Corker EA, Beldie A, Brain C, Jakovljevic M, Jarema M, Karanustafalioglu O, Marksteiner J, Mohr P, Prelipceanu D, Vasileache A, Waern M, Sartorius N, Thornicroft G, FEDORA study group (2015) Experience of stigma and discrimination reported by people experiencing the first episode of schizophrenia and those with a first episode of depression: the FEDORA project. *Int J Soc Psychiatry* 61:438–445
- Hamilton S, Corker E, Weeks C, Williams P, Henderson C, Pinfold V, Rose D, Thornicroft G (2016) Factors associated with experienced discrimination among people using mental health services in England. *J Ment Health*. <https://doi.org/10.3109/09638237.2016.1139068>
- Schomerus G, Schwahn C, Holzinger A, Corrigan PW, Grabe HJ, Carta MG, Angermeyer MC (2012) Evolution of public attitudes about mental illness: a systematic review and meta-analysis. *Acta Psychiatr Scand* 125:440–452
- Angermeyer MC, Matschinger H, Carta MG, Schomerus G (2014) Changes in the perception of mental illness stigma in Germany over the last two decades. *Eur Psychiatry* 29:390–395
- Hayes SC (2004) Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behav Ther* 35:639–665
- Brohan E, Slade M, Clement S, Thornicroft G (2010) Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Serv Res*. <https://doi.org/10.1186/1472-6963-10-80>
- Jacoby A (1994) Felt versus enacted stigma: a concept revisited. Evidence from a study of people with epilepsy in remission. *Soc Sci Med* 38:269–274
- Link BG, Cullen FT, Struening E, Shrout PE, Dohrenwend BP (1989) A modified labeling theory approach to mental disorders: an empirical assessment. *Am Sociol Rev* 54:400–423
- Ritsher JB, Phelan JC (2004) Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Res* 129:257–265
- Corrigan PW, Rafacz J, Rüschi N (2011) Examining a progressive model of self-stigma and its impact on people with serious mental illness. *Psychiatry Res* 189:339–343
- Gaebel W, Rössler W, Sartorius N (2016) The stigma of mental illness—end of the story? Springer, Cham
- Hall SA (2009) The social inclusion of people with disabilities: a qualitative metaanalysis. *J Ethnogr Qual Res* 3:162–173
- Corrigan PW, Larson JE, Rüschi N (2009) Self-stigma and the “why try” effect: impact on life goals and evidence-based practices. *World Psychiatry* 8:75–81
- Lasalvia A, Zoppei S, Bonetto C, Tosato S, Zanatta G, Cristofalo D, De Santi K, Bertani M, Bissoli S, Lazzarotto L, Ceccato E, Riolo R, Marangon V, Cremonese C, Boggian I, Tansella M, Ruggeri M (2014) The role of experienced and anticipated discrimination in the lives of people with first-episode psychosis. *Psychiatr Serv* 65:1034–1040
- Gronholm PC, Thornicroft G, Laurens KR, Evans-Lacko S (2017) Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: a systematic review. *Psychol Med* 47:1867–1879
- Chen ES, Chang WC, Hui CL, Chan SK, Lee EH, Chen EY (2016) Self-stigma and affiliate stigma in first-episode psychosis

- patients and their caregivers. *Soc Psychiatry Psychiatr Epidemiol* 51:1225–1231
26. Mittal D, Sullivan G, Chekuri L, Allee E, Corrigan PW (2012) Empirical studies of self-stigma reduction strategies: a critical review of the literature. *Psychiatr Serv* 63:974–981
  27. Sibitz I, Provaznikova K, Lipp M, Lakeman R, Amering M (2013) The impact of recovery-oriented day clinic treatment on internalized stigma: preliminary report. *Psychiatry Res* 209:326–332
  28. Zäske H, Sauter S, Ohmann C, Icks A, Gaebel W (2013) Stärkung von Empowerment und Stigma-Bewältigungskompetenz bei Menschen mit psychischen Erkrankungen. Poster PO2-4 Patientenorientierung IV, 12. Deutscher Kongress für Versorgungsforschung; Deutsches Netzwerk Versorgungsforschung, 23.–25. Oktober 2013, Berlin
  29. Roe D, Hasson-Ohayon I, Mashiach-Eizenberg M, Derhy O, Lysaker PH, Yanos PT (2014) Narrative enhancement and cognitive therapy (NECT) effectiveness: a quasi-experimental study. *J Clin Psychol* 70:303–312
  30. Zäske H (2016) The influence of stigma on illness course. In: Gaebel W, Rössler W, Sartorius N (eds) *The stigma of mental illness—end of the story?* Springer, Cham, pp 141–155
  31. Ho RWH, Chang WC, Kwong VWY, Lau ESK, Chan GHK, Jim OTT, Hui CLM, Chan SKW, Lee EHM, Chen EYH (2017) Prediction of self-stigma in early psychosis: 3-year follow-up of the randomized-controlled trial on extended early intervention. *Schizophr Res*. <https://doi.org/10.1016/j.schres.2017.09.004> (**Epub ahead of print**)
  32. Crisp AH, Gelder MG, Rix S, Meltzer HI, Rowlands OJ (2000) Stigmatisation of people with mental illnesses. *Br J Psychiatry* 177:4–7
  33. Corrigan P (2004) How stigma interferes with mental health care. *Am Psychol* 59:614–625
  34. Tanskanen S, Morant N, Hinton M, Lloyd-Evans B, Crosby M, Killaspy H, Raine R, Pilling S, Johnson S (2011) Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study. *BMC Psychiatry*. <https://doi.org/10.1186/1471-244X-11-157>
  35. McGorry PD, Killackey E, Yung A (2008) Early intervention in psychosis: concepts, evidence and future directions. *World Psychiatry* 7:148–156
  36. Rüschen N, Heekeren K, Theodoridou A, Müller M, Corrigan PW, Mayer B, Metzler S, Dvorsky D, Walitza S, Rössler W (2015) Stigma as a stressor and transition to schizophrenia after one year among young people at risk of psychosis. *Schizophr Res* 166:43–48
  37. Xu Z, Müller M, Heekeren K, Theodoridou A, Dvorsky D, Metzler S, Brabban A, Corrigan PW, Walitza S, Rössler W, Rüschen N (2016) Self-labelling and stigma as predictors of attitudes towards help-seeking among people at risk of psychosis: 1-year follow-up. *Eur Arch Psychiatry Clin Neurosci* 266:79–82
  38. Zäske H, Degner D, Jockers-Scherübl M, Klingberg S, Klosterkötter J, Maier W, Möller HJ, Sauer H, Schmitt A, Gaebel W (2016) Experiences of stigma and discrimination in patients with first-episode schizophrenia. (Article in German). *Der Nervenarzt* 87:82–87
  39. Gaebel W, Riesbeck M, Wölwer W, Klimke A, Eickhoff M, von Wilmsdorff M, Jockers-Scherübl MC, Kühn KU, Lemke M, Bechdorf A, Bender S, Degner D, Schlösser R, Schmidt LG, Schmitt A, Jäger M, Buchkremer G, Falkai P, Klingberg S, Köpcke W, Maier W, Häfner H, Ohmann C, Salize HJ, Schneider F, Möller HJ (2007) German study group on first-episode schizophrenia. Maintenance treatment with risperidone or low-dose haloperidol in first-episode schizophrenia: 1-year results of a randomized controlled trial within the German Research Network on Schizophrenia. *J Clin Psychiatry* 68:1763–1774
  40. Riesbeck M, von Wilmsdorff M, Krohmer R, Wölwer W, Bottlender R, Möller HJ, Gaebel W (2004) Optimization of long-term treatment strategies in first episode patients with schizophrenia. (Article in German). *Psychoneuro* 30:615–619
  41. Kemp R, David A (1996) Psychological predictors of insight and compliance in psychotic patients. *Br J Psychiatry* 169:444–450
  42. Schooler N, Hogarty G, Weissman M (1979) Social adjustment scale II (SAS-II). In: Hargreaves WA, Atkisson CC, Sorenson JE (eds) *Resource materials for community mental health program evaluations*. DHEW, Washington, DC, pp 79–328
  43. Kay SR, Opler LA, Fiszbein A (1986) The positive and negative syndrome scale (PANSS) rating manual. *Soc Behav Sci Doc* 17:28–29
  44. Guy W, Bethesda MD (1976) *Clinical global impressions (CGI) scale*. In: Guy W (ed) *ECDEU assessment manual for psychopharmacology, revised*. US Department Health, Education, and Welfare, Washington, DC, pp 218–222
  45. Addington D, Addington J, Schissel B (1990) A depression rating scale for schizophrenics. *Schizophr Res* 3:247–251
  46. Frances A, Pincus HA, First MB (1994) The global assessment of functioning scale (GAF). In: *Diagnostic and statistical manual of mental disorder—IV*. American Psychiatric Association, Washington, DC, p 32
  47. Oliver JP, Huxley PJ, Priebe S, Kaiser W (1997) Measuring the quality of life of severely mentally ill people using the Lancaire quality of life profile. *Soc Psychiatry Psychiatr Epidemiol* 32:76–83
  48. Deusinger IM (1986) *Frankfurter Selbstkonzeptskalen (FSKN)*. Hogrefe, Göttingen
  49. Linden M, Nather J, Wilms HU (1988) Definition, significance and measurement of illness concepts of patients. The “Illness Concept Scale (KK-Scale)” for Schizophrenic Patients. (Article in German). *Fortschr Neurol Psychiatr* 56:35–43
  50. Bortz J, Lienert GA (2003) *Kurzgefasste Statistik für die klinische Forschung. Leitfaden für die verteilungsfreie Analyse kleiner Stichproben*. (Compact statistics for clinical research. Guideline for the nonparametric analysis of small samples), 2nd edn. Springer, Heidelberg
  51. Kenny DA, Harackiewicz JM (1979) Cross-lagged panel correlation: practice and promise. *J Appl Psychol* 64:372–379
  52. Link BG, Struening EL, Rahav M, Phelan JC, Nuttbrock L (1997) On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *J Health Soc Behav* 38:177–190
  53. Corker E, Hamilton S, Henderson C, Weeks C, Pinfold V, Rose D, Williams P, Flach C, Gill V, Lewis-Holmes E, Thornicroft G (2013) Experiences of discrimination among people using mental health services in England 2008–2011. *Br J Psychiatry* 202:s58–s63
  54. Thornicroft C, Wyllie A, Thornicroft G, Mehta N (2014) Impact of the “Like Minds, Like Mine” anti-stigma and discrimination campaign in New Zealand on anticipated and experienced discrimination. *Aust N Z J Psychiatry* 48:360–370
  55. Rose D, Willis R, Brohan E, Sartorius N, Villares C, Wahlbeck K, Thornicroft G, INDIGO Study Group (2011) Reported stigma and discrimination by people with a diagnosis of schizophrenia. *Epidemiol Psychiatr Sci* 20:193–204
  56. Linden M, Godemann F (2007) The differentiation between ‘lack of insight’ and ‘dysfunctional health beliefs’ in schizophrenia. *Psychopathology* 40:236–241
  57. Link BG, Phelan JC (2001) Conceptualizing stigma. *Annu Rev Sociol* 27:363–385
  58. Angermeyer M, Schomerus G (2012) A stigma perspective on recovery. *World Psychiatry* 11:163–164
  59. Major B, O’Brien LT (2005) The social psychology of stigma. *Annu Rev Psychol* 56:393–421

60. Mueller B, Nordt C, Lauber C, Rueesch P, Meyer PC, Roessler W (2006) Social support modifies perceived stigmatization in the first years of mental illness: a longitudinal approach. *Soc Sci Med* 62:39–49
61. Corrigan PW, Watson AC, Barr L (2006) The self-stigma of mental illness: implications for self-esteem and self-efficacy. *J Soc Clin Psychol* 25:875–884