



Longitudinal course of self-labeling, stigma stress and well-being among young people at risk of psychosis



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ABSTRACT

Stigma may undermine the well-being of young people at risk of psychosis. We therefore measured self-labeling, stigma variables and well-being at baseline and again one year later among 77 at-risk participants. An increase in self-labeling during this period predicted heightened stigma stress after one year and a decrease in stigma stress predicted better well-being at follow-up, controlling for symptoms, psychiatric comorbidity and sociodemographic variables. Besides early intervention programmes, strategies are needed to reduce the public stigma associated with at-risk status and to support young people at risk to better cope with self-labeling and stigma stress.

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1. Introduction

Early intervention programmes for schizophrenia and bipolar disorder have become more common worldwide with the promise of considerable clinical benefits for young people at risk of these disorders (Fusar-Poli et al., 2013). However, symptoms of the emerging illness as well as early intervention itself may lead to labeling or self-labeling as 'mentally ill'. The resulting (self-)stigma could harm the well-being of young people at risk irrespective of clinical symptoms (Yang et al., 2010), but longitudinal quantitative data on the impact of self-labeling and stigma variables on their well-being are lacking.

In a previous cross-sectional analysis of the current sample at baseline (Rüsçh et al., 2014b), we found associations of perceived stigma, shame and self-labeling with increased stigma-related stress; and of more stigma stress with reduced well-being. Therefore the aims of the current study were twofold: first, to confirm these cross-sectional findings in longitudinal analyses; and second, to use a stress-coping model of mental illness stigma (Rüsçh et al., 2009a, 2009b) to identify relevant stigma mechanisms as targets for future interventions. This model is based on Lazarus' and Folkman's (1984) work on stress appraisal

processes and on identity threat models of stigma (Major and O'Brien, 2005); stigma stress occurs if persons with mental illness feel that stigma-related harm exceeds their perceived resources to cope with stigma. We assessed (i) self-labeling, shame and perceived stigma as predictors of stigma stress after one year; and (ii) stigma stress as predictor of well-being after one year. Regarding these predictor variables, we examined their baseline scores as well as their change scores, from baseline to one-year follow-up, as predictors of stigma or well-being after one year, respectively.

2. Methods

2.1. Participants

Participants were recruited in the region of Zürich, Switzerland, for a longitudinal observational study among young people at risk of psychosis (Rüsçh et al., 2013, 2014b). The current analyses are based on the baseline and 1-year follow-up data of this project (for details of baseline data, recruitment, in- and exclusion criteria, and sample characteristics see Rüsçh et al., 2014b). All participants provided written informed consent, in case of minors including the parents' written informed consent. The study was approved by the regional ethics committee. Participants fulfilled at least one of the following three inclusion criteria: (i) high-risk status for psychosis assessed by the adult (Schultze-Lutter et al.,

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2007) or children–youth (Schultze-Lutter and Koch, 2009) version of the Schizophrenia Proneness Interview; or (ii) ultra-high-risk status for psychosis as rated by the Structured Interview for Prodromal Syndromes (Miller et al., 2003); or (iii) risk for bipolar disorder, defined by a score ≥ 14 in the Hypomania Checklist (Angst et al., 2005). At follow-up, data were available from 77 participants (45% of the baseline sample (n = 172); age M = 20.3, SD = 5.5; 46% female), of whom at baseline 69 (90%) had fulfilled high risk, 38 (49%) ultra-high risk criteria for psychosis, and 59 (77%) risk criteria for bipolar disorder. Ninety-five individuals could not be contacted for follow-up assessment, had discontinued the study or provided incomplete data.

2.2. Measures

2.2.1. Predictors of stigma stress

Perceived public stigma was measured by Link's (1987) 12-item Perceived Devaluation-Discrimination Questionnaire (baseline/follow-up scores of the 77 completers in our study: M = 3.4/3.5, SD = 1.0/1.0). Shame about one's mental illness was rated by the item 'I would feel ashamed to have a mental illness' from 1 (not at all) to 9 (very much) (baseline/follow-up: M = 4.5/4.3, SD = 2.3/2.6). Self-labeling as 'mentally ill' was measured as how participants perceived their mental health, from 1 ('I am perfectly mentally healthy') to 9 ('I am severely mentally ill') (baseline/follow-up M = 4.9/4.2, SD = 1.8/2.0).

2.2.2. Stigma stress, well-being and symptoms

The cognitive appraisal of mental illness stigma as a stressor was assessed by the 8-item Stigma Stress Scale (Rüsç et al., 2009b, 2014c), which yields a difference score of stigma stress by subtracting perceived resources to cope with stigma from perceived stigma-related harm, higher difference scores indicating more stigma stress (baseline/follow-up: M = -1.7/-1.7, SD = 2.3/2.5). Quality of life was assessed by 12 subjective items of the Manchester Short Assessment of Quality of life (Priebe et al., 1999) (baseline/follow-up: M = 4.2/4.7, SD = 1.1/1.2). Self-esteem was measured by Rosenberg's 10-item self-esteem scale (Rosenberg, 1965) (baseline/follow-up: M = 1.6/1.9, SD = 0.8/0.8). Self-efficacy was examined using Schwarzer and Jerusalem's (1995) 10-item general self-efficacy scale (baseline/follow-up: M = 2.6/2.7, SD = 0.7/0.6). As in the baseline data analyses (Rüsç et al., 2014b), due to high intercorrelations we averaged quality of life, self-esteem and self-efficacy into one well-being score. The mean scores of each of these three scales were transformed into percentile scores and then averaged into a single percentile score. Symptoms were assessed

by the Positive and Negative Syndrome Scale (Kay et al., 1987), yielding positive (baseline/follow-up: M = 12.8/10.8, SD = 3.9/4.2) and negative symptom scores (baseline/follow-up: M = 13.8/12.1, SD = 6.0/6.4).

2.3. Analyses

Using multiple linear regressions we assessed whether (i) baseline scores and (ii) baseline/follow-up change scores of predictor variables (perceived public stigma, shame, self-labeling as 'mentally ill') were associated with stigma stress at follow-up, controlling for baseline levels of stigma stress; and whether (i) baseline score and (ii) baseline/follow-up change score of stigma stress were associated with well-being at follow-up, controlling for well-being baseline levels. Both regression models were adjusted for age, gender, symptom levels and psychiatric comorbidity.

3. Results

3.1. Comparing participants at follow-up with dropouts

The 95 individuals who did not participate in the 1-year follow-up assessment did not differ significantly from the 77 participants who completed it in terms of baseline sociodemographic or clinical variables, except for completers being younger (M = 20.3 years; SD = 5.5) than dropouts (M = 22.1; SD = 5.8; t = 2.06; df = 170; p = .04) and fulfilling at baseline more often high risk criteria than dropouts (90% versus 75%, chi-square = 6.2, p = .01). At a trend level, dropouts perceived more discrimination (M = 3.7, SD = 0.1) than completers (M = 3.4, SD = 0.1; t = 1.93; df = 170, p = .055) at baseline and had more major depression diagnoses (61% versus 48%, chi-square = 2.91, p = .09).

3.2. Predictors of stigma stress and of well-being

In multiple linear regressions the baseline levels of perceived stigma, shame or self-labeling were not significantly associated with stigma stress after one year, nor were baseline levels of stigma stress predictive of well-being at follow-up (results not shown in Table 1). However, an increase in self-labeling from baseline to follow-up predicted higher stigma stress after one year (Table 1); and an increase in stigma stress predicted poorer well-being after one year, after adjusting for age, gender, symptoms, psychiatric comorbidity and the baseline level of stigma stress or well-being, respectively (Table 1). All predictors accounted for nearly half of stigma stress' or well-being's variance, respectively.

Table 1
Multiple linear regressions examining predictors of stigma stress (upper half) and predictors of well-being (lower half) at 1-year follow-up.

Dependent variable	Independent variables	beta	T	p	R ²
Stigma stress after one year	Change of perceived public stigma ^(a)	.14	1.28	.20	.47
	Change of shame ^(a)	.18	1.64	.11	
	Change of self-labeling as 'mentally ill' ^(a)	.25	2.25	.03	
	Change of positive symptoms ^(a)	-.03	-0.26	.80	
	Change of negative symptoms ^(a)	.17	1.52	.13	
	Age	-.06	-0.59	.56	
	Gender	.14	1.41	.16	
	Depressive disorder (0 = no, 1 = yes) ^(b)	-.21	-1.94	.06	
	Anxiety disorder (0 = no, 1 = yes) ^(b)	.07	.66	.51	
	Stigma stress at baseline	.52	4.74	<.001	
Well-being after one year	Change of stigma stress ^(a)	-.21	-2.04	.045	.47
	Change of positive symptoms ^(a)	-.03	-0.28	.78	
	Change of negative symptoms ^(a)	-.07	-0.59	.56	
	Age	-.14	-1.40	.17	
	Gender	.15	1.59	.12	
	Depressive disorder (0 = no, 1 = yes) ^(b)	-.11	-1.06	.29	
	Anxiety disorder (0 = no, 1 = yes) ^(b)	-.07	-0.68	.29	
	Well-being at baseline	.51	4.71	<.001	

^(a) Difference scores are computed such that positive values indicate an increase from baseline to one-year follow-up, negative values a decrease.
^(b) at baseline.

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