

Self-stigma as a barrier to recovery: a longitudinal study

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Abstract Stigma limits life opportunities of persons with mental illness. Self-stigma, the internalization of negative stereotypes, undermines empowerment and could hinder recovery. Here we examined self-stigma's effect on recovery among 222 disability pensioners with mental illness over 2 years, controlling for age, gender, symptoms and recovery at baseline measured by the Recovery Assessment Scale. More self-stigma at baseline was associated with a significant decrease in recovery after 1 year (not significant after 2 years). An increase of self-stigma from baseline to follow-up predicted less recovery 1 and 2 years later. Interventions that reduce self-stigma could therefore improve recovery.

Keywords Mental illness · Self-stigma · Recovery

Introduction

Persons with mental illness are not only distressed by symptoms, but by stigma that inhibits their life opportunities. Stereotypes, prejudice and discriminating behaviours among the public (=public stigma) lead to inequalities in employment, housing and treatment availability as well as social exclusion of individuals with mental illness [1]. Another harmful facet of mental illness stigma

is self-stigma, the internalization of stereotypes, which diminishes self-esteem, self-efficacy and self-respect. As a consequence individuals with mental illness may lose hope and question their worthiness and capability to pursue recovery goals [2]. Recovery from mental illness has been described as an individual process, not limited to symptom reduction but including the empowerment to live a self-determined and fulfilling life [3]. Undermining empowerment and diminishing self-efficacy, self-stigma may be a major threat to recovery. Previous cross-sectional studies found self-stigma to be negatively associated with recovery [2, 4–6]. Self-stigma was also shown to be associated with recovery-related variables, such as low self-esteem, poor quality of life, reduced empowerment, hopelessness and increased psychiatric symptoms [7]. One longitudinal study found baseline stigma levels to predict recovery 6 months later but did not measure self-stigma [8]. Being modifiable by interventions [9], self-stigma could be addressed to foster recovery. In addition to programs decreasing self-stigma using psychoeducation, narrative approaches or peer-support [9], interventions to reduce public stigma are likely to also decrease self-stigma [10]. To provide robust empirical evidence for self-stigma's effect on recovery, longitudinal evidence is needed. Controlling for baseline recovery and symptom levels, we expected that: (1) more self-stigma at baseline or (2) an increase in self-stigma from baseline to follow-up would predict less recovery 1 and 2 years later.

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Methods

Design and participants

Two-hundred and fifty persons participated in a two-arm randomized controlled trial (ISRCTN54951166, Zurich

integration pilot project; <http://www.zhepp.ch>) testing the efficacy of supported employment (individual placement and support, IPS) to re-integrate disability pensioners with mental illness into competitive employment (i.e. jobs in the free labour market) [11, 12]. Persons were eligible to participate if they lived in the Canton of Zurich, Switzerland, were 18–60 years old, in psychiatric/psychotherapeutic treatment, received disability pensions due to mental illness for no more than 1 year, and sought competitive employment. After providing written informed consent, participants were randomly assigned to the intervention (IPS) or treatment as usual (TAU). Participants were followed over 2 years and self-stigma and recovery were assessed at baseline as well as after 1 and 2 years. After excluding individuals with missing data, at baseline 222 individuals remained for analyses, 168 individuals after 1 year, and 155 after 2 years. To control for potential intervention effects we included group status (IPS vs. TAU) in all regression analyses.

Measures

For all measures higher mean scores reflected increased levels of the measured variables. Recovery was measured by the 24-item Recovery Assessment Scale [13], covering five dimensions of recovery: personal confidence and hope (e.g. “I am hopeful about my future”), willingness to ask for help (e.g. “I ask for help when I need it”), goal and success orientation (e.g. “I have goals in life that I want to reach”), reliance to others (e.g. “I have people I can count on”) and no domination by symptoms (e.g. “My symptoms interfere less and less with my life”). Total mean scores from 1 to 5 were calculated (baseline: $M=3.52$, $SD=0.59$, min/max: 1.5/5.0, Cronbach’s alpha: 0.87; 1-year follow-up: $M=3.54$, $SD=0.60$, min/max: 1.5/4.8, Cronbach’s alpha: 0.89; 2-year follow-up: $M=3.54$, $SD=0.64$, min/max: 1.0/4.8, Cronbach’s alpha: 0.90). The 29-item Internalized Stigma of Mental Illness Scale (ISMI) [14] assessed self-stigma with mean scores from 1 to 4 (baseline: $M=2.10$, $SD=0.56$, min/max: 1.0/3.9, Cronbach’s alpha: 0.89; 1-year follow-up: $M=2.13$, $SD=0.56$, min/max: 1.1/3.7, Cronbach’s alpha: 0.90; 2-year follow-up: $M=2.11$, $SD=0.56$, min/max: 1.1/3.7, Cronbach’s alpha: 0.90). Psychopathology was assessed by the Symptom Checklist-90-revised [15], yielding a Global Severity Index (GSI) as mean score across all items (baseline: $M=1.21$, $SD=0.73$, min/max: 0/3.9; 1-year follow-up: $M=1.19$, $SD=0.68$, min/max: 0/3.2; 2-year follow-up: $M=1.08$, $SD=0.67$, min/max: 0/3.3). Psychiatric ICD-10 diagnoses were obtained from participants’ disability pension records with 46% diagnosed with affective disorders, 16% schizophrenia/schizoaffective disorders, 17% personality disorders and 18% other mental disorders.

Statistical analysis

As appropriate, independent *t* tests or Chi-square tests were used to compare completers (baseline $N=222$; 1-year follow-up $N=168$; 2-year follow-up $N=155$) and non-completers regarding baseline measures. Bivariate associations between independent variables and recovery were assessed using Pearson’s correlations. Finally, two sets of linear regression models (set 1: controlled for recovery at baseline; set 2: additionally controlled for GSI, age, gender and group status) tested the association between self-stigma at baseline or self-stigma change scores (calculated as: score at 1 or 2-year follow-up—score at baseline, positive difference scores indicating an increase of self-stigma over time) and recovery 1 and 2 years later.

Results

Completers and non-completers did not differ significantly regarding baseline measures (recovery, self-stigma, GSI, age, gender, group status; all $p>0.20$). At baseline, participants were on average 43 years old (range 19–60, $M=42.8$, $SD=10.3$) and evenly distributed in terms of gender (female: $n=117$, 53%; male: $n=105$, 47%) and group status (IPS: $n=113$, 51%; TAU: $n=109$, 49%). Age, gender and group status were not significantly associated with recovery at any assessment point (all $p>0.10$). Self-stigma and GSI at baseline were significantly (all $p<0.001$) and negatively associated with recovery at baseline ($r=-0.58$, $r=-0.53$, respectively), 1-year follow-up ($r=-0.58$, $r=-0.50$, respectively) and 2-year follow-up ($r=-0.43$, $r=-0.37$, respectively).

Controlling for GSI, age, gender and group status, more self-stigma at baseline predicted less recovery at baseline and after 1 year. After 2 years, this negative effect of baseline self-stigma on recovery was no longer significant. On the other hand, an increase of self-stigma from baseline to follow-up was negatively related to recovery 1 and 2 years later (Table 1).

Discussion

As hypothesised and consistent with previous cross-sectional studies [2, 4–6] our findings provide first evidence of a longitudinal and potentially causal relationship between self-stigma and recovery. The association between baseline self-stigma and follow-up recovery was limited to about 1 year. This may be due to successful coping of some individuals when self-stigma does not increase over time. Accordingly when change scores were analysed, an increase in self-stigma from baseline to follow-up led to significantly less recovery 1

Table 1 Linear regression models predicting recovery at baseline as well as after 1 and 2 years

	Independent variables	Dependent variables								
		Recovery baseline			Recovery 1-year follow-up			Recovery 2-year follow-up		
		(n=222)			(n=168)			(n=155)		
		β	95%CI	R^2	β	95%CI	R^2	β	95%CI	R^2
Set 1	Recovery at baseline	–		0.33**	0.56**	0.43 to 0.68	0.54**	0.59**	0.46 to 0.78	0.42**
	Self-stigma at baseline	–0.58**	–0.73 to –0.50		–0.25**	–0.41 to –0.14		–0.09	–0.27 to 0.07	
	Recovery at baseline	–		–	0.73**	0.63 to 0.83	0.56**	0.67**	0.59 to 0.82	0.54**
Set 2 ^a	Self-stigma change scores	–			–0.25**	–0.65 to –0.27		–0.36**	–0.77 to –0.42	
	Recovery at baseline	–		0.39**	0.53**	0.39 to 0.66	0.54**	0.59**	0.45 to 0.78	0.43**
	Self-stigma at baseline	–0.42**	–0.59 to –0.30		–0.21*	–0.39 to –0.07		–0.09	–0.29 to 0.10	
	Recovery at baseline	–		–	0.63**	0.51 to 0.75	0.58**	0.64**	0.54 to 0.81	0.57**
	Self-stigma change scores	–			–0.25**	–0.64 to –0.27		–0.38**	–0.79 to –0.44	

β standardized linear regression coefficient, CI confidence interval for B (unstandardized regression coefficient)

* $p < 0.01$, ** $p < 0.001$

^aControlled for GSI, age, gender and group status [IPS vs. TAU]

and 2 years later. Our findings therefore indicate that recovery from mental illness could be improved by interventions supporting persons with mental illness to cope with self-stigma soon after a first psychiatric diagnosis [9]. Self-stigma could be reduced both at an individual level [9, 16, 17] and by addressing public stigma [10, 18].

Strengths and limitations of our study need to be briefly considered. Recovery was assessed by a well-established scale. Data were derived from a sample of disability pensioners, a hard-to-reach population, therefore generalizability is limited. To enhance understanding of the nature of the relationship between stigma and recovery, potential mediators (e.g. self-esteem) and the role of public stigma variables (perceived, experienced and structural discrimination) should be examined. For example, as societal stigma is the root of self-stigma [2], it could have both indirect and direct effects on recovery. If our findings are replicated, self-stigma interventions could be integrated in programs to enhance recovery.

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Conflict of interest None.

Ethical approval The study was approved by the ethics committee of the canton of Zurich (reference number: KEK-ZH-NR: 2010–0311/0).

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