Stigma, well-being, attitudes to service use and transition to schizophrenia: Longitudinal findings among young people at risk of psychosis

Nicolas Rüsch, Mario Müller, Karsten Heekeren,
Ana Theodoridou, Wulf Rössler

Dept of Psychiatry II, University of Ulm & BKH Günzburg, Germany

Psychiatric University Hospital Zürich, Switzerland

Background I: Stigma - an issue for at-risk states and intervention?

- Labeling as ‚mentally ill' possible due to
  - emerging symptoms
  - early intervention

- Concerns raised in the literature, cf. discussion about inclusion of at-risk syndrome in DSM-5
  (Corcoran et al 2010; Yang et al 2010)

- No quantitative data on stigma among people at risk of psychosis   (qualitative: Judge et al 2008)

Background II: Mechanisms

Models to explain how public stigma and self-stigma / shame could negatively affect young people at risk:

1. Modified Labeling Theory (Bruce Link):

After being labeled, public attitudes become self-relevant

2. Stress-coping models of stigma (Lazarus; Major & O'Brien 2005):

Stigma stress, if perc'd harm exceeds perc'd coping resources.

Questions

1. Do labeling and stigma variables predict reduced well-being among people at risk of psychosis after one year?

2. Do stress-coping models explain how stigma affects this group?

3. Does stigma stress predict transition to schizophrenia?

Cross-sectional findings

Rüsch et al, Psych Serv 2014
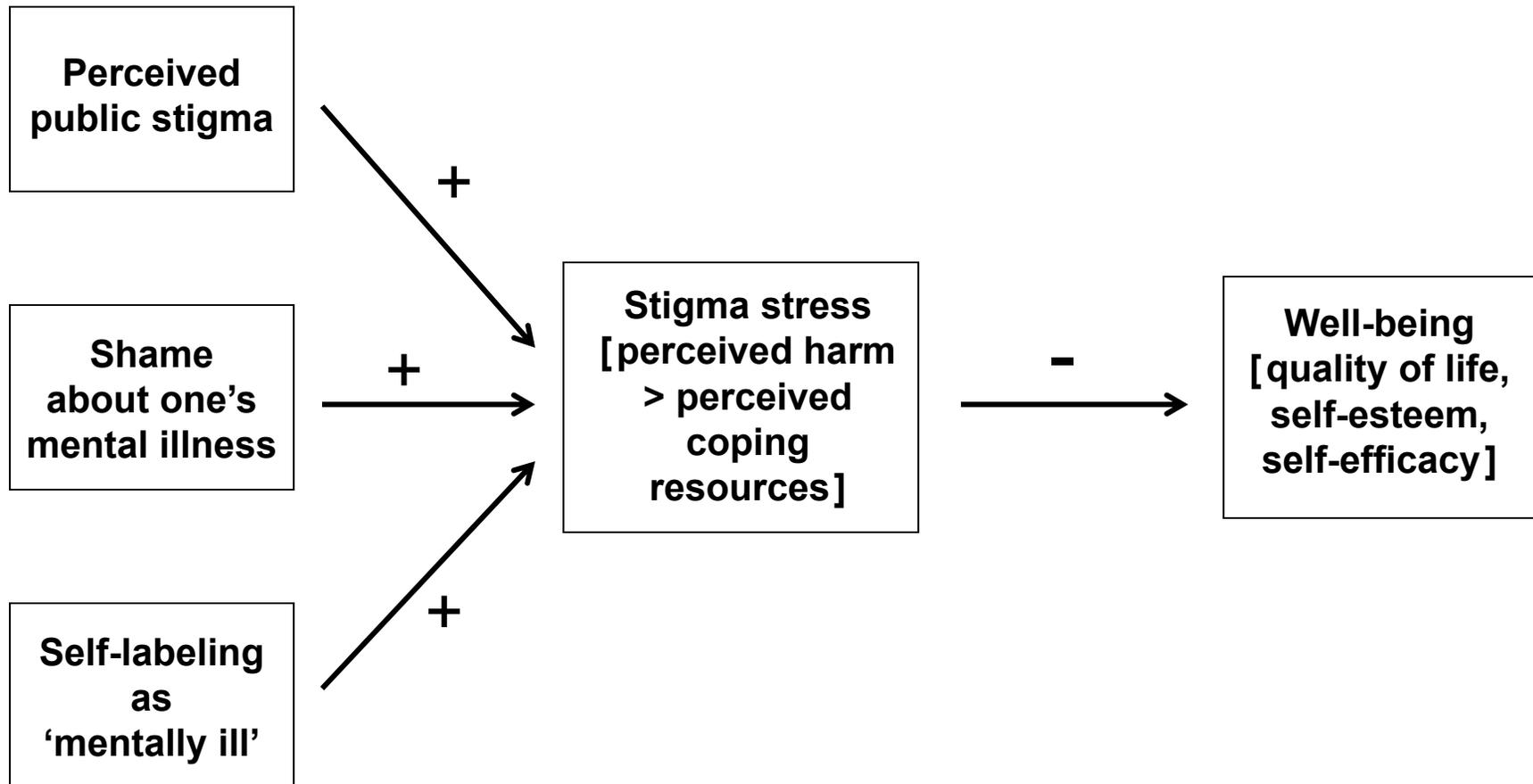
Methods I: Participants

- N=77, 13 to 35 years old (mean 20), 46% female
  (45% of baseline sample, n=172)

- Recruitment via website, schools, GPs, counseling services, psychiatrists etc.

- Inclusion if one or more criteria met at baseline [% baseline]:
- high risk for psychosis (Schizophrenia Proneness Interview, Schultze-Lutter et al 2007) [80%]
- ultra-high risk for psychosis (Structured Interview for Prodromal Syndromes; Miller et al 2003) [49%]
- bipolar risk (Hypomania Checklist; Angst et al 2005) [79%]

Overlap: 42% both with high and ultra-high risk for psychosis; 13% only at risk for bipolar disorder

Methods II: Predictors of stigma stress

- Perceived public stigma: Perceived Devaluation-Discrimination Questionnaire, Link et al 1987

- Shame: ,I would feel ashamed to have a mental illness', rated from 1 to 9

- Self-labeling: How do you perceive your mental health?, rated from 1 / „I am perfectly mentally healthy" to 9 / „I am severely mentally ill"

Methods III: Stigma stress

Stigma Stress Scale (Kaiser et al 2004; Rüsch et al 2009)

4 items on primary appraisal of stigma as harmful (α=.92)

4 items on secondary appraisal of perceived resources to cope with stigma (α=.77)

Stress appraisal score = perceived harm – coping resources

→ higher difference score = more stigma stress

Methods IV: Well-being and symptoms

Well-being as mean score (corr. 0.51 to 0.69) of

- subjective QoL (Manchester Short Assessment of QoL, Priebe et al 1999; α=.82)

- general self-esteem (Rosenberg 1965, α=.92)

- general self-efficacy (Schwarzer & Jerusalem 1995; α=.91)

Positive and Negative Syndrome Scale (Kay et al 1987)

# Results I: Change in predictor variables and stigma stress after one year

DV	IVs	beta	p	R²
	Change of perceived public stigma	.14	.20	
	Change of shame	.18	.11	
	Change of self-labeling as 'mentally ill'	.25	.03	
	Change of positive symptoms	-.03	.80	
Stigma stress after one year	Change of negative symptoms	.17	.13	
	Age	-.06	.56	
	Gender	.14	.16	
	Depressive disorder (0=no, 1=yes)	-.21	.06	
	Anxiety disorder (0=no, 1=yes)	.07	.51	
	Stigma stress at baseline	.52	<.001	.47

Results II: Change in stigma stress and well-being after one year

DV	IVs	beta	p	R²
Well-being after one year	Change of stigma stress	-.21	.045	
	Change of positive symptoms	-.03	.78	
	Change of negative symptoms	-.07	.56	
	Age	-.14	.17	
	Gender	.15	.12	
	Depressive disorder (0=no, 1=yes)	-.11	.29	
	Anxiety disorder (0=no, 1=yes)	-.07	.29	
	Well-being at baseline	.51	<.001	.47

Longitudinal findings [Summary]

Rüsch et al, Sz Res 2014
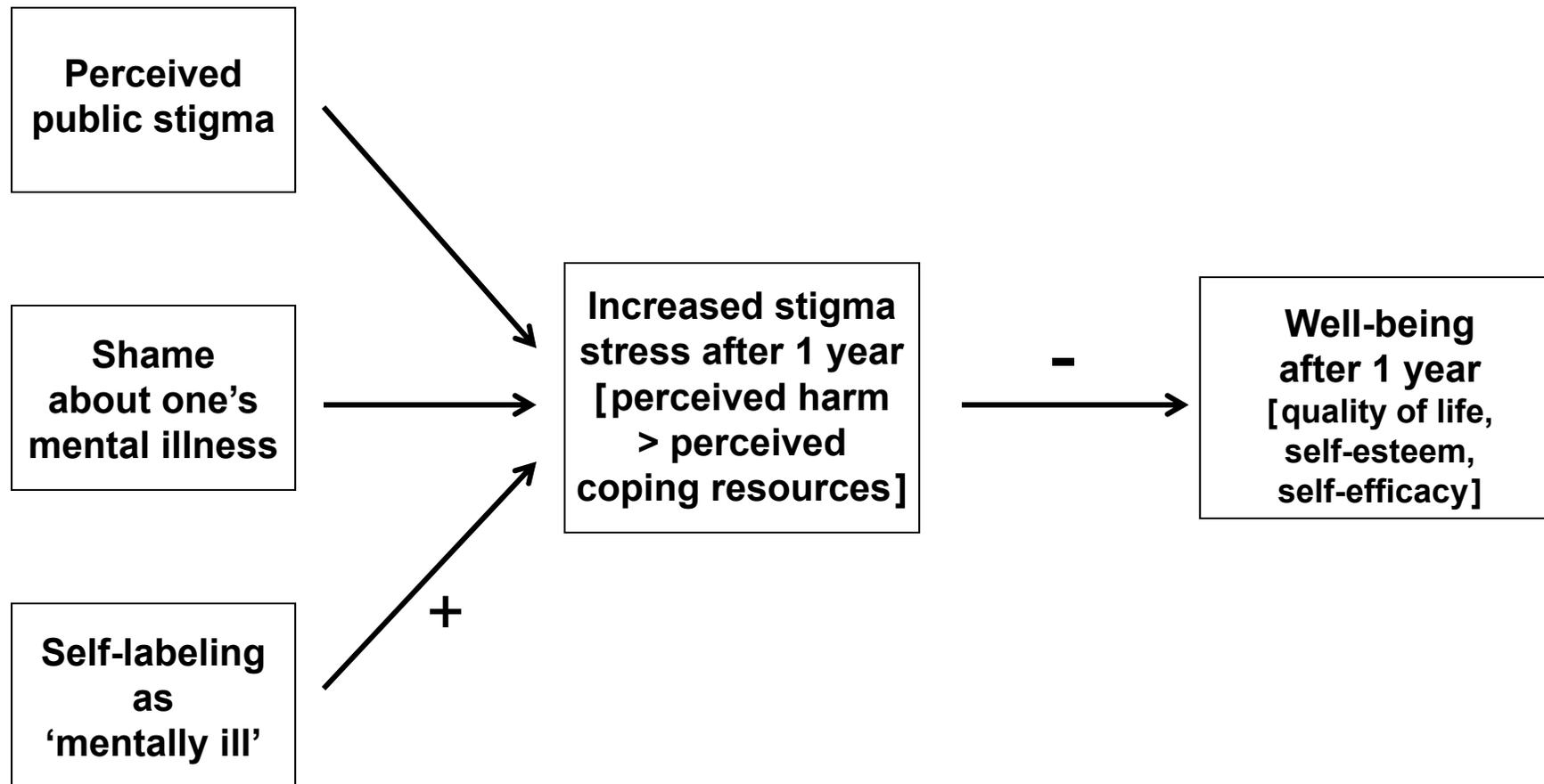
Stigma Stress and Transition to Schizophrenia
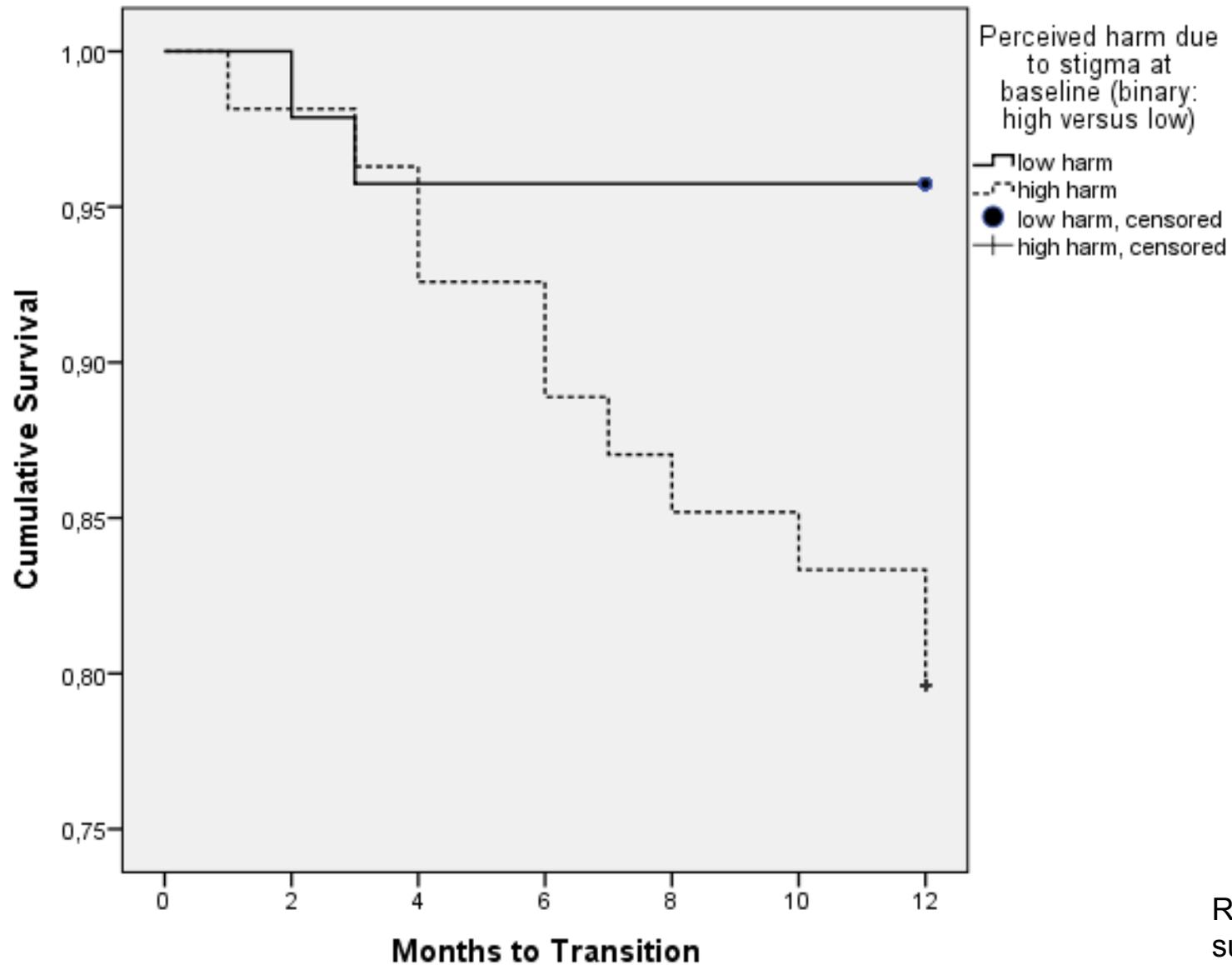
Rüsch et al, submitted

Prediction of Transition to Sz after 1 year: Log. Regression

Independent variables	Odds Ratios (95%-CI)	p	ORs (95%-CI)	p
Positive symptoms (PANSS)	1.34 (1.10-1.63)	.004	1.38 (1.08-1.77)	.012
Negative symptoms (PANSS)	1.21 (1.05 – 1.39)	.009	1.16 (0.99-1.36)	.07
Appraisal of stigma as harmful	2.05 (1.14 – 3.69)	.017	2.34 (1.19-4.60)	.013
Age			0.95 (0.81-1.12)	.55
Gender			1.49 (0.23-9.74)	.68
Resources to cope with stigma			0.87 (0.39-1.94)	.73
Global functioning (GAF)			0.98 (0.92-1.04)	.51

Discussion I: General aims

Change of self-labeling and of stigma stress associated with poorer well-being among young people at risk
→ stigma as an issue for early intervention
→ targets for programs to reduce stigma's impact

Stress-coping models helpful to understand mechanisms.

Discussion II: Labeling

Mental illness label - a two-edged sword for people at risk?

- may facilitate help-seeking

- may increase vulnerability to stigma

Discussion III: Symptoms / Dx

- Role of stigma variables independent of symptoms and psychiatric diagnoses

- Cognitive appraisal of stigma as a stressor

- a key determinant of stigma's impact?

- risk factor for transition to schizophrenia?

→ possible target for interventions

Discussion IV: Limitations

- Labeling experiences unclear

- Role of social environment unclear

- Baseline scores not predictive [except for transition]

- High dropout rate, low transition rate

- No comparison group of people with established psychosis

Questions

- Labeling and stigma as the price we pay for early intervention? (problem of about 2/3 false positives)

- How can early intervention reach out to people at risk with minimal labeling/stigma?

- How can we reduce stigma's impact for this group (without blaming them for shame/self-stigma)?

Thank you for your attention!

Email: nicolas.ruesch@uni-ulm.de

Inclusion Criteria

(i) high-risk status for psychosis assessed by the adult (Schultze-Lutter *et al.* 2007) or children-youth (Schultze-Lutter and Koch, 2009) version of the Schizophrenia Proneness Interview, with at least one cognitive-perceptive basic symptom or at least two cognitive disturbances;

or

(ii) ultra-high-risk status for psychosis as rated by the Structured Interview for Prodromal Syndromes (Miller *et al.* 2003), with at least one attenuated psychotic symptom, or at least one brief limited intermittent psychotic symptom, or state-trait criteria (reduction in global assessment of functioning of >30% in the past year, plus either schizotypal personality disorder or first degree relative with psychosis)

or

(iii) risk for bipolar disorder, defined by a score ≥14 in the Hypomania Checklist, a self-report measure of life-time hypomanic symptoms (Angst *et al.* 2005).