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

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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?
Perceived public stigma

Shame about one’s mental illness

Self-labeling as ‘mentally ill’

Stigma stress [perceived harm > perceived coping resources]

Well-being [quality of life, self-esteem, self-efficacy]

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 ($\alpha=.92$)
4 items on secondary appraisal of perceived resources to cope with stigma ($\alpha=.77$)

Stress appraisal score = perceived harm – coping resources

$\rightarrow$ 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

<table>
<thead>
<tr>
<th>DV</th>
<th>IVs</th>
<th>beta</th>
<th>p</th>
<th>R²</th>
</tr>
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<tbody>
<tr>
<td>Stigma stress after one year</td>
<td>Change of perceived public stigma</td>
<td>.14</td>
<td>.20</td>
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<tr>
<td></td>
<td>Change of shame</td>
<td>.18</td>
<td>.11</td>
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<tr>
<td></td>
<td>Change of self-labeling as ‘mentally ill’</td>
<td>.25</td>
<td>.03</td>
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<tr>
<td></td>
<td>Change of positive symptoms</td>
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<td>.80</td>
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<td>Change of negative symptoms</td>
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<td>.13</td>
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<td></td>
<td>Age</td>
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<td></td>
<td>Gender</td>
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<td>.16</td>
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<tr>
<td></td>
<td>Depressive disorder (0=no, 1=yes)</td>
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<td>.06</td>
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<tr>
<td></td>
<td>Anxiety disorder (0=no, 1=yes)</td>
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<td></td>
<td>Stigma stress at baseline</td>
<td>.52</td>
<td>&lt;.001</td>
<td>.47</td>
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</table>
### Results II: Change in stigma stress and well-being after one year

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<thead>
<tr>
<th>DV</th>
<th>IVs</th>
<th>beta</th>
<th>p</th>
<th>R²</th>
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</thead>
<tbody>
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<td><strong>Change of stigma stress</strong></td>
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<td><strong>Change of positive symptoms</strong></td>
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<td><strong>Change of negative symptoms</strong></td>
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<tr>
<td><strong>Well-being after one year</strong></td>
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<td>.17</td>
<td></td>
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<tr>
<td></td>
<td>Gender</td>
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<td>.12</td>
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<tr>
<td></td>
<td>Depressive disorder (0=no, 1=yes)</td>
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<td>Anxiety disorder (0=no, 1=yes)</td>
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</table>
Longitudinal findings [Summary]

- Perceived public stigma
- Shame about one’s mental illness
- Self-labeling as ‘mentally ill’

Increased stigma stress after 1 year [perceived harm > perceived coping resources]

Well-being after 1 year [quality of life, self-esteem, self-efficacy]

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

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Odds Ratios (95%-CI)</th>
<th>p</th>
<th>ORs (95%-CI)</th>
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<tbody>
<tr>
<td>Positive symptoms (PANSS)</td>
<td>1.34 (1.10-1.63)</td>
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<td>1.38 (1.08-1.77)</td>
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<tr>
<td>Negative symptoms (PANSS)</td>
<td>1.21 (1.05 – 1.39)</td>
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<td>1.16 (0.99-1.36)</td>
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<td>Appraisal of stigma as harmful</td>
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<td>2.34 (1.19-4.60)</td>
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<tr>
<td>Gender</td>
<td>1.49 (0.23-9.74)</td>
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<td>Resources to cope with stigma</td>
<td>0.87 (0.39-1.94)</td>
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<td>Global functioning (GAF)</td>
<td>0.98 (0.92-1.04)</td>
<td>.51</td>
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</table>
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)?
This study was supported by the Zürich Impulse Program for the Sustainable Development of Mental Health Services (www.zinep.ch).

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).