What is actually known about the relationship between stigma and medication adherence - myth or reality?

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Statement of Potential Conflicts of Interest

Relating to this presentation, there are no relationships that could be perceived as potential conflict of interests:

Brain C, Sameby B, Allerby K, Quinlan P, Joas E, Lindström E, Burns T, Waern M
What is stigma?

Schizophrenia is one of the most stigmatized mental disorders.

Stigma reduces the rate of help-seeking and diminishes access to medical exams, diagnostics, care and treatments for both psychiatric and physical illnesses.

A concept that exists to different degrees in all cultures and a problem of:

- **Knowledge** (= ignorance or misinformation)
- **Attitude** (= prejudice)
- **Behaviour** (= discrimination)

What is Non-Adherence?

Non-adherence is defined as the number of doses not taken or taken incorrectly that jeopardizes the patient’s therapeutic outcome, including:¹, ²

- Not having a prescription filled
- Taking an incorrect dose
- Taking a medication at the wrong time
- Forgetting to take doses or stopping therapy too soon

Partial Adherence: A Primary Treatment Challenge

Non-adherence
Few or no meds taken
= not taking medication as prescribed
missing doses
drug holidays
lower dose Rx

Partial adherence
Some doses taken
– often erratically

Acceptable adherence
>70%-80% of meds taken

Docherty et al 2002; Valenstein et al 2002; Kane 1983
Key factors associated with non-adherence in schizophrenia
Modified from Haddad, Brain, Scott 2014
Drivers of non-adherence

- Poor insight/cognition
- Complicated/inconvenient regimens
- Substance abuse
- Positive symptoms
- Poor social support
- Intolerable side effects/AEs
- Patient attitudes to treatment

Haddad PM, Brain C, Scott J. Patient Related Outcome Measures. 2014:5.43-62
Strategies to Assess Adherence

Objective
- Observed intake
- Biological markers
- Pill count
- MEMS®
- MPR
- Plasma levels?

Subjective
- Ratings
- Diary
- Questionnaires
- Scales, DAI, MARS

The MEMS®, Electronic Medication Monitoring
An objective measure of adherence ($\leq 0.8$)
Patient Adherence Report

Patient number: 0DIST124
Clinic: NÅUt-team et
Monitor number: 268414

Results: 30/12/2009 03:00:00 to 12/08/2009 02:59:00 (1)

Drug: Clozapine 100mg
Regimen: 1 X per day

June 2009

July 2009

August 2009

The patient missed 1 or 2 consecutive days of medication (estimated over intervisit): 20 days
Medication omissions were exceptionally frequent on (estimated over the entire follow-up): Friday
The patient opened the bottle more often within a 24 hour period than required by the dosing regimen (estimated over intervisit): 9
Drug attitude and other predictors of medication adherence in schizophrenia: 12 months of electronic monitoring (MEMS®) in the Swedish COAST-study

Cecilia Brain\textsuperscript{a,b,*}, Katarina Allerby\textsuperscript{b}, Birgitta Sameby\textsuperscript{b}, Patrick Quinlan\textsuperscript{a,b}, Erik Joas\textsuperscript{a}, Ulla Karilampi\textsuperscript{c}, Eva Lindström\textsuperscript{d}, Jonas Eberhard\textsuperscript{e}, Tom Burns\textsuperscript{f}, Margda Waern\textsuperscript{a}
## Results

Univariate logistic regression models predicting MEMS® non-adherence.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Adherent (n = 81)</th>
<th>Non-adherent (n = 31)</th>
<th>OR (CI95%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PANSS, positive subscale</td>
<td>20.4 (14 – 37)</td>
<td>22.5 (15 - 33)</td>
<td>1.01 (1.01 - 1.20)</td>
</tr>
<tr>
<td>Judgment and insight (G12 PANSS)</td>
<td>3.6 (2 - 6)</td>
<td>4.1 (2 - 6)</td>
<td>1.61 (1.08 - 2.42)</td>
</tr>
<tr>
<td>DAI-10</td>
<td>6.2 (-4 - 10)</td>
<td>2.4 (-10 - 10)</td>
<td>0.79 (0.70 - 0.90)</td>
</tr>
<tr>
<td>PSP</td>
<td>49.2 (30 - 75)</td>
<td>42.8 (30 - 68)</td>
<td>0.94 (0.91 - 0.99)</td>
</tr>
<tr>
<td>Side-effects (psychiatric)</td>
<td>1.6 (1.0 - 3.0)</td>
<td>1.9 (1.0 - 3.20)</td>
<td>3.95 (1.60 - 9.80)</td>
</tr>
</tbody>
</table>

Values denote mean (range) if not specified otherwise.
PANSS, Positive and Negative Syndrome Scale Schizophrenia
DAI, Drug Attitude Inventory
PSP, Personal and Social Performance Scale
## Results

Age and gender adjusted multivariate logistic regression model predicting MEMS® non-adherence.

<table>
<thead>
<tr>
<th>Variable</th>
<th>OR</th>
<th>CI95%</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.96</td>
<td>0.92 - 1.03</td>
<td>.070</td>
</tr>
<tr>
<td>Gender</td>
<td>1.77</td>
<td>0.60 - 4.99</td>
<td>.269</td>
</tr>
<tr>
<td>DAI-10</td>
<td>0.71</td>
<td>0.69 - 0.89</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>PSP</td>
<td>0.94</td>
<td>0.90 - 0.98</td>
<td>.007</td>
</tr>
</tbody>
</table>

1 At the “optimal” DAI cut-off at 4, one-third of the adherent patients would still be falsely identified as non-adherent.
Stigma, discrimination and medication adherence in schizophrenia: Results from the Swedish COAST study

Cecilia Brain\textsuperscript{a,b,\ast}, Birgitta Sameby\textsuperscript{b}, Katarina Allerby\textsuperscript{b}, Patrick Quinlan\textsuperscript{a,b}, Erik Joas\textsuperscript{a}, Eva Lindström\textsuperscript{c}, Tom Burns\textsuperscript{d}, Margda Waern\textsuperscript{a}

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\textsuperscript{b} Psychosis Clinic, Sahlgrenska University Hospital, Gothenburg, Sweden
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ABSTRACT

The aims of this naturalistic non-interventional study were to quantify the level of stigma and discrimination in persons with schizophrenia and to test for potential associations between different
Demographic and clinical characteristics of patients at baseline

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total (n = 111)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male/female), n</td>
<td>70/41</td>
</tr>
<tr>
<td>Age, years</td>
<td>45.8 (11.1)</td>
</tr>
<tr>
<td>Education, years n (≤ 12 / &gt;12)</td>
<td>48/63</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>97 (87.4)</td>
</tr>
<tr>
<td>Living situation, n (%)</td>
<td></td>
</tr>
<tr>
<td>Independent</td>
<td>63 (56.8)</td>
</tr>
<tr>
<td>Substance and alcohol abuse, n (%)</td>
<td>36 (32.4)</td>
</tr>
<tr>
<td>Sick-leave, disability retirement</td>
<td>93 (83.8)</td>
</tr>
<tr>
<td>Duration of illness, years n (%)</td>
<td></td>
</tr>
<tr>
<td>&gt;15</td>
<td>62 (55.9)</td>
</tr>
<tr>
<td>Ratings</td>
<td></td>
</tr>
<tr>
<td>Remission (SCI-SR), n (%)</td>
<td>60 (54.1)</td>
</tr>
<tr>
<td>Function (GAF)</td>
<td>45.1 (10.1)</td>
</tr>
</tbody>
</table>

SCI-SR = The Structured Clinical Interview for Symptoms of Remission; GAF = Global Assessment of Functioning
The Discrimination and Stigma Scale (DISC-12)

Structured interview to measure discrimination and stigmatization in mental illness (32 Items)

Four DISC-12 subscales:
• experienced discrimination (ED)
• anticipated discrimination (AD)
• overcoming stigma (OS)
• positive treatment due to the mental illness (P)
Proportion of valid DISC item responses (n=111)

Results

Social relations
- Making friends 71%
- By neighbours 69%

In psychiatry 50%

Shunned 62%
- Avoidance 70%
- Concealed 88%

Coping 78%
Results

Proportions of patients (n=111) with DISC subscale ratings (≥ “a little”) were:

- experienced discrimination  31.5%
- anticipated discrimination  64.8%
- overcoming stigma        63.1%
- positive treatment       5.4%

No association was found between non-adherence (n=30, 27.3%) and the DISC subscale mean scores (adjusted for DAI and PSP).
Results

Patients with lower skills to cope with stigma were more likely classified as non-adherent

Univariate and multivariate logistic regression models predicting MEMS® non-adherence by mean DISC subscale scores of the Discrimination and Stigma Scale

<table>
<thead>
<tr>
<th>Variable</th>
<th>Univariate</th>
<th>Multivariate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR  CI (95%)  p-value</td>
<td>OR  CI (95%)  p-value</td>
</tr>
<tr>
<td>Experienced discrimination</td>
<td>1.05 0.41 - 2.68 .926</td>
<td>0.55 0.18 - 1.69 .294</td>
</tr>
<tr>
<td>Anticipated discrimination</td>
<td>1.37 0.78 - 2.39 .276</td>
<td>0.87 0.45 - 1.68 .669</td>
</tr>
<tr>
<td><strong>Overcoming stigma</strong></td>
<td>0.50 0.28 - 0.91 .024</td>
<td>0.80 0.39 - 1.65 .552</td>
</tr>
<tr>
<td>Positive treatment</td>
<td>0.33 0.08 - 1.45 .141</td>
<td>0.47 0.96 - 2.32 .354</td>
</tr>
</tbody>
</table>

Multivariate regression models were adjusted for drug attitude (Drug Attitude Inventory 10 Items, DAI-10) and psychosocial function (Personal and Social Performance Scale, PSP).
Discussion and Conclusions

• To our knowledge this is the first study to employ an objective measure of adherence and a valid stigma measure to study the association between adherence and stigma in schizophrenia.

• Non-adherence was observed in 27%.

• Adherent patients had better abilities to overcome stigma.

• Drug attitude was a predictor of adherence and also associated with overcoming stigma.

• Function and anticipated discrimination were associated.
Discussion and Conclusions

• Almost two-thirds felt discriminated within the area of social relationships.

• Half felt discriminated by mental health staff.

• One-third felt discriminated when seeking physical health care.

• In adjusted models there was no association between stigma and adherence.

• Larger studies are needed to study the association between stigma and adherence.
Thank you!

cecilia.brain@vgregion.se
## Stigma and Adherence: The COAST study

### Experienced discrimination (DISC-12)

<table>
<thead>
<tr>
<th>Stigma (indicated ‘yes’)</th>
<th>Proportion of patients (%) (n = 111)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping or making friends</td>
<td>71</td>
</tr>
<tr>
<td>Discrimination by neighbours</td>
<td>69</td>
</tr>
<tr>
<td>Avoided due to diagnosis</td>
<td>62</td>
</tr>
<tr>
<td>Discrimination by family</td>
<td>55</td>
</tr>
<tr>
<td>Finding/keeping work</td>
<td>52</td>
</tr>
<tr>
<td>Intimate/sexual relationship</td>
<td>51</td>
</tr>
<tr>
<td>Discrimination by mental health staff</td>
<td>50</td>
</tr>
<tr>
<td>Disadvantage medical attention</td>
<td>36</td>
</tr>
<tr>
<td>Safety and security</td>
<td>35</td>
</tr>
<tr>
<td>Disadvantage in housing</td>
<td>31</td>
</tr>
<tr>
<td>Disadvantage in welfare benefits</td>
<td>20</td>
</tr>
</tbody>
</table>

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The Sahlgrenska Academy
Anticipated discrimination (DISC-12)

<table>
<thead>
<tr>
<th>Stigma (indicated ‘yes’)</th>
<th>Proportion of patients (%) (n = 111)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concealed mental health problem</td>
<td>88</td>
</tr>
<tr>
<td>Personal relationships</td>
<td>70</td>
</tr>
<tr>
<td>Applying for work</td>
<td>51</td>
</tr>
<tr>
<td>Applying for education</td>
<td>43</td>
</tr>
</tbody>
</table>

Brain C, Sameby B, Allerby K, Quinlan P, Joas E, Burns T, Lindström E, Waern M
Stigma and Adherence: The COAST study

Overcoming stigma (DISC-12)

Coping skill (indicated ‘yes’)

Proportion of patients (%) (n = 111)

0 10 20 30 40 50 60 70 80 90

Personal skills to cope with discrimination

Friends outside mental health care system

78
52

Brain C, Sameby B, Allerby K, Quinlan P, Joas E, Burns T, Lindström E, Waern M
## Stigma and Adherence: The COAST study

### Positive treatment (DISC-12)

<table>
<thead>
<tr>
<th>Discrimination (indicated ‘yes’)</th>
<th>Proportion of patients (%) (n = 111)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive treatment by family</td>
<td>51</td>
</tr>
<tr>
<td>Advantage in employment</td>
<td>10</td>
</tr>
<tr>
<td>Advantage in welfare benefits/disability pensions</td>
<td>9</td>
</tr>
<tr>
<td>Advantage in housing</td>
<td>8</td>
</tr>
<tr>
<td>Advantage in religious activities</td>
<td>3</td>
</tr>
</tbody>
</table>

Brain C, Sameby B, Allerby K, Quinlan P, Joas E, Burns T, Lindström E, Waern M