Self-stigma and adherence to medication in patients with psychotic disorders – cross-sectional study

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Abstract

OBJECTIVE: Adherence to treatment of mental disorders is one of the key factors influencing its success and, secondarily, the patients’ quality of life and social adaptation. The cross-sectional study of 90 outpatients diagnosed with psychotic disorders aimed at determining if there was a relationship between discontinuation of psychoactive drugs in the past, current adherence to treatment and self-stigma.

METHODS: The assessment was made with the objective and subjective Clinical Global Impression – Severity scale, Drug Attitude Inventory, Internalized Stigma of Mental Illness (ISMI) scale and demographic data. The questionnaires were filled out by 79 patients, of whom 5 handed in incomplete questionnaires. Complete sets of data were obtained from 74 patients.

RESULTS: The data analysis showed that the levels of self-stigma as assessed by the total ISMI scores was not statistically significantly correlated with most of the demographic factors (age, age of illness onset, gender, education, marital status, employment, duration of the illness, number of hospitalizations and antipsychotic dosage). However, there was a significant negative correlation with current adherence to treatment.

INTRODUCTION

Most individuals diagnosed with schizophrenia have to deal with some form of stigmatization (Dickerson et al. 2002; Lee et al. 2006). Stigmatization refers to a stereotypical set of negative attitudes, incorrect beliefs and fear associated with the diagnosis of schizophrenia influenced by how the syndrome is perceived by others. The public perception of schizophrenia is formed by a lack of knowledge, prejudice and discriminating behavior and may be further reinforced by a scientifically simplistic emphasis on the biogenetic model of the disease on the part of some professionals (Angermeyer & Matschinger 2005; Thornicroft et al. 2007; Lincoln et al. 2008). In an effort to avoid labeling, stigmatization may lead to delays in seeking help and treatment. Subsequent psychological and
social harms may further aggravate the condition itself and lead to further impairment of mental functions. In particular, the threat of social disapproval or diminished self-esteem accompanying this label is associated with underuse of health and social services (Corrigan et al. 2004). Moreover, schizophrenia-related prejudice and discrimination result in poor adherence to therapy (Villares & Sartorius 2003). Awareness of illness and insight may produce better functional outcome but if insight is accompanied by acceptance of stigmatizing attitudes it is more likely to impair social functioning and decrease hope and self-esteem (Lysaker et al. 2007).

Research on stigmatization had been mostly concerned with the general public’s negative attitudes towards individuals with schizophrenia. Less frequently, attitudes of patients exposed to stigmatization are studied. Self-stigma is a process by which patients assign themselves a derogatory or socially disabling label, internalize it and expect other people to treat them in a negative way, reject or despise them (Yanos et al. 2008; Rüsch et al. 2009; Margetić et al. 2010). After internalization, the process works on its own without the person having to be aware of what he or she does to himself or herself and others (Schulze & Angermeyer 2003; Alonso et al. 2009). Internalization of stigma occurs when an individual notices that others begin to treat him or her in a different, less friendly, way, and realizes the prejudice leading to such behavior. Then he or she starts to believe that the public views of and attitudes towards persons with mental disorders are justified. In the last phase, the person applies the stereotypes to one's self, strongly agrees with them and acts according with them (Corrigan et al. 2011). A recent systematic review (Gerlinger et al. 2013) showed that one third to one half of patients with schizophrenia spectrum disorders were ashamed of their illness and experienced alienation as the most frequent aspect of self-stigma. In the review, self-stigma predicted more depression and social anxiety, lower quality of life, and less self-esteem, social functioning, hope, vocational functioning, recovery and adherence to treatment. Self-stigma is associated with decreased self-esteem and self-confidence, lower social and vocational functioning, increased severity of symptoms and lower compliance (Cavelti et al. 2011; Kleim et al. 2008; Sirey et al. 2001; Wahl 1999; Watson et al. 2007; Yanos et al. 2008; Yanos et al. 2010). Recent studies showed that the prevalence of self-stigmatizing attitudes in individuals suffering from severe mental disorders in Europe was 42% and 36% (Brohan et al. 2010; West et al. 2011). The more patients and their families perceive psychiatric diagnoses as a stigma and the more they expect rejection from coworkers or friends, the more difficult is their treatment. There are similar prejudices about psychiatric treatment itself. In addition to labeling of mental illness, this is another reason for avoiding psychiatry even though it is apparent that the person needs therapy. Psychoactive drugs are considered to be little effective, unsuitable for causal therapy, produce sedation and stupor, induce dependence, have negative effects on the brain and body. This is mainly how antipsychotics are perceived. Thus, stigma, and mainly self-stigma, substantially affects adherence to medication (Assefa et al. 2012), leading to fear as a source of a mental burden. This in turn has a negative impact on the course of the illness.

Adherence to treatment in patients with psychotic disorders is a serious issue due to numerous reasons associated with patients’ inadequate compliance. These include a significantly increased relapse risk after discontinuation of medication, complications in the long-term course of the disease and more frequent hospital stays. The psychosocial factors related to inadequate adherence to therapy are especially a lack of insight into the illness (Latalova 2014), fear of stigma and self-stigma (Livingston & Boyd 2010; Outcalt & Lysaker 2012), poor therapeutic relationship and discouraging the loved ones from taking medication (Schulze & Angermeyer 2003). An effort to avoid labeling, leading to denying the illness and delaying or avoiding treatment, may be the most important barrier to help-seeking (Barney et al. 2009; Gumley et al. 2004; Vrbová et al. 2013).

Fung et al. (2010) explored the link between self-stigma, treatment adherence, psychopathology, insight and readiness for change in 105 patients with schizophrenia recruited from 5 psychiatric facilities in Hong Kong. The results showed a direct impact of self-stigma and psychopathology on psychosocial treatment adherence and an indirect influence mediated by insight and readiness for change on the overall treatment adherence. At the same time, self-stigma was found to have no direct effect on the level of psychopathology. Tsang et al. (2010) studied the relationship between self-stigma, readiness for change and psychosocial program adherence in 105 schizophrenic patients. Stepwise multiple regression showed that individuals with higher global functioning were more ready for change, had lower levels of self-stigma and demonstrated better treatment participation.

The present study aimed at determining the levels of stigmatization and adherence in stable psychiatric outpatients diagnosed with schizophrenia spectrum disorders, their interrelationship, relationships to discontinuation of prescribed medication in the past, current severity of their illness and possibly other demographic data. The objective was to verify the following hypotheses: (a) the levels of stigmatization and non-adherence or medication withdrawal are higher in younger patients, males, patients without a partner and those with lower education; (b) higher levels of self-stigma are associated with lower adherence and more frequent discontinuation of psychoactive drugs; and (c) patients who discontinued their medication by their own will in the past have lower current treatment adherence and higher self-stigma levels.
METHOD

Patients
Participation in the study was offered to patients diagnosed with schizophrenia spectrum disorders (schizophrenia, schizoaffective disorder, delusional disorder) regularly attending a psychiatry department outpatient center who met the following criteria: (a) schizophrenia spectrum psychotic disorder (F2X) according to the ICD-10 criteria (1992); (b) willingness to fill out questionnaires; (c) age between 18 and 75 years; and (d) controlled mental disorder (the patient is able to attend outpatient treatment and has a long-term stable disease that requires no hospital stay).

Excluded were patients with mental retardation, organic mental disorder, severe physical illness and those with acute exacerbation and thus in need for hospitalization, an increase or change in medication or psychotherapeutic crisis intervention. The participants attended the outpatient center for regular check-ups and were treated with standard medication for the defined group of diagnoses in accordance with the relevant guidelines and principles of good practice (EMEA 2002).

Assessment tools
Internalized Stigma of Mental Illness (ISMI) is a scale consisting of 29 items with a four-point scale that measures 5 areas of internalized stigma (Ritsher et al. 2003). These areas include feelings of alienation and exclusion from society, the degree of consent to the stereotypes about people with mental illness, perception of how others have behaved toward them since they were diagnosed as mentally ill, rate of withdrawal from society, and the degree of resistance to the stigma (Boyd et al. 2014). The Czech version of the scale was standardized by Ociskova et al. (2014).

Drug Attitude Inventory (DAI-10) is a questionnaire designed to assess patients’ attitude to medication. The patient identifies each statement as true or false. The statements are concerned with the effects of the medication, its necessity and voluntary use. It assesses the current level of adherence (that is, not the patient’s decision to continue or discontinue medication in the past).

Clinical Global Impression (CGI; Guy 1976) is a scale for an overall assessment of the severity of psychopathology. The source of evaluation is a comprehensive assessment of the patient’s physician. In its subjective version (CGI-S), the patient evaluates the overall condition by himself/herself on a 1–7 scale, wherein each of the degrees of severity has described features.

Demographic questionnaire contains basic information such as gender, age, employment, marital status, pension income, education, age of illness onset, overall time of attending the outpatient center, number of hospitalizations, time elapsed since the last hospitalization, number of visited psychiatrists, current medication, and information about discontinued medication in the past (either on recommendation of a psychiatrist or by one’s own will).

Statistical evaluation and ethics
The results were processed with the statistical software Prism (GraphPad PRISM version 5.0; http://www.graphpad.com/prism/prism.htm). Demographic data and mean total scores in the individual questionnaires and CGI scales were assessed using descriptive statistics to identify the mean, median, standard deviation, and the character of the data distribution. The mean values were compared with the t-test. The relationships between individual categories were assessed by correlation coefficients and linear regression. The relationships between alternative variables (gender, marital status, discontinuation of medication) were assessed by the Fisher test. The meanings of the correlations of the individual factors were analyzed using backward stepwise regression. A 5% level of significance was considered acceptable for all statistical tests.

The study was approved by the local ethics committee. The research was conducted in accordance with the latest version of the Helsinki Declaration and Guideline for Good Clinical Practice (EMEA 2002). The participants gave informed written consent.

RESULTS

Group characteristics
The questionnaires were offered to a total of 90 patients with schizophrenia attending a psychiatry department outpatient center. Of those, 74 patients (82.2%) volunteered to fill out all the questionnaires. The reasons for not completing the questionnaires were lack of time, loss of motivation during completion of the two questionnaires (it was tiring), inability to concentrate on the questions in the waiting room, and absence of corrective appliances (glasses). The final results were calculated for the 74 patients who provided all the necessary data. Those who were excluded from the study for not completing the questionnaires were statistically significantly older than the subgroup who filled them out (Table 1). The two subgroups did not statistically significantly differ on any of the demographic or clinical parameters.

The clinical entities most frequently identified as the main diagnosis were schizophrenia and schizoaffective disorder, followed by schizotypal disorder, acute and transient psychotic disorders, and permanent delusional disorder (Figure 1).

The investigated group comprised 41.8% of women. At the time of assessment, antipsychotics were used by 97.5% of the participants, antidepressants by 36.7%, anxiolytics by 15.2% and mood stabilizers by 8.9% of the patients. The mean doses were 4.77±3.15 mg (risperidone index) for antipsychotics, 27.37±17.41 mg (paroxetine index) for antidepressants and 7.11±7.37 mg (diazepam index) for anxiolytics in those using the
drugs. In the past, 55.7% of the patients had discontinued their medication without consultation with their physicians. A total of 68.4% of the patients were single, 17.7% were married, 12.7% were divorced and one patient was a widow (Figure 1).

Nearly one-half (48.1%) of the patients had a positive family history of mental disorder; of those, 21% had a relative with schizophrenia spectrum disorder. The achieved education levels were as follows: primary (13.9%), vocational (24.1%), secondary (40.5%) and tertiary (21.5%) (Figure 1).

Self-stigma, adherence and discontinuation of medication in relation to demographic and clinical variables

Family history of mental disorder

The mean levels of self-stigma and adherence to treatment in patients with no family history of mental disorder were practically identical to those in patients with a positive family history. Similarly, there was no difference between the two subgroups in the proportion of patients who had discontinued their medication in the past by their own will and without their physician’s recommendation (Table 2).

Gender

The mean levels of self-stigma were similar in both genders; there was no statistically significant difference between the two genders. Similarly, there was no statistically significant difference in the levels of current adherence to treatment between the genders. Finally, there was no gender difference in voluntary discontinuation of medication (Table 2).

Partnership status

When comparing patients living without a partner (65.8%) with those living with their partners, the mean levels of self-stigma, adherence and voluntary discontinuation of psychoactive drugs were similar. There was no statistically significant difference between the two subgroups (Table 2).

Education

The levels of self-stigma were not associated with the levels of education (one-way ANOVA: F=0.9657 df=75; n.s.; Figure 2).

There were no statistically significant differences in the mean levels of current adherence in relation to the levels of education completed (one-way ANOVA: F=1.652 df=77; n.s.; Figure 3).

Although the patients with tertiary education admitted discontinuation of medication by their own will less frequently (35%) than the others, there was no statistically significant difference between the subgroups (chi-square: 0.6410, 3; p = n.s.; Figure 4).
## Tab. 2. Self-stigma, adherence and discontinuation of medication in relation to a family history of mental disorder, gender, partnership status and discontinued medication.

<table>
<thead>
<tr>
<th>Level of stigma</th>
<th>Statistics – group comparison</th>
<th>Adherence to treatment</th>
<th>Statistics – group comparison</th>
<th>Frequency of discontinued medication in the past</th>
<th>Statistics – group comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history</td>
<td></td>
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</tr>
<tr>
<td>No family history</td>
<td>59.03 ± 12.25 unpaired t-test: t=0.7991 df=72; n.s.</td>
<td>3.108 ± 3.928</td>
<td>unpaired t-test: t=0.4815 df=73; n.s.</td>
<td>34.0%</td>
<td>Fisher's exact test: n.s.</td>
</tr>
<tr>
<td>Men</td>
<td>59.21 ± 12.86 unpaired t-test: t=0.7969; df=72; n.s.</td>
<td>3.282 ± 4.690</td>
<td>unpaired t-test: t=0.8770 df=73; n.s.</td>
<td>46.3%</td>
<td>Fisher's exact test: n.s.</td>
</tr>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With a partner</td>
<td>59.10 ± 12.59 unpaired t-test: t=0.4988 df=72; n.s.</td>
<td>2.421 ± 4.598</td>
<td>unpaired t-test: t=0.5247 df=73; n.s.</td>
<td>55.0%</td>
<td>Fisher's exact test: n.s.</td>
</tr>
<tr>
<td>Without a partner</td>
<td>60.87 ± 13.89</td>
<td></td>
<td></td>
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<tr>
<td>Discontinued medication</td>
<td>61.74 ± 13.31 unpaired t-test: t=0.4558 df=76; n.s.</td>
<td>2.800 ± 4.398</td>
<td>unpaired t-test: t=0.1281 df=75; n.s.</td>
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<tr>
<td>Taken medication</td>
<td>60.33 ± 13.93</td>
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</tr>
</tbody>
</table>

## Tab. 3. Correlation of ISMI and DAI-10 scores with demographic and clinical data.

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Onset of illness</th>
<th>Number of hospitalizations</th>
<th>Number of outpatient psychiatrists</th>
<th>adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation with the total ISMI score</td>
<td>0.02634 P</td>
<td>0.1416 P</td>
<td>0.1054 S</td>
<td>0.1783 S</td>
<td>-0.3653 P</td>
</tr>
<tr>
<td>antipsychotic dosage (risperidone index, n=72)</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td>p&lt;0.005</td>
</tr>
<tr>
<td>antidepressant dosage (paroxetine index, n=46)</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>anxiolytic index (diazepam index, n=22)</td>
<td>CGI-S</td>
<td>CGI-O</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Correlation with the total ISMI score</td>
<td>0.1237 S</td>
<td>0.3962 S</td>
<td>-0.2311 P</td>
<td>0.04979 S</td>
<td>0.07928 S</td>
</tr>
<tr>
<td>Age</td>
<td>p&lt;0.01</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
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<tr>
<td>Onset of illness</td>
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<td>Number of hospitalizations</td>
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<tr>
<td>Number of outpatient psychiatrists</td>
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<tr>
<td>total ISMI score</td>
<td></td>
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<tr>
<td>Correlation with the total DAI-10 score</td>
<td>-0.01834 P</td>
<td>0.06027 P</td>
<td>0.02776 S</td>
<td>-0.05435 S</td>
<td>-0.3653 P</td>
</tr>
<tr>
<td>antipsychotic dosage (risperidone index, n=72)</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td>p&lt;0.005</td>
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<td>CGI-S</td>
<td>CGI-O</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Correlation with the total DAI-10 score</td>
<td>-0.02736 S</td>
<td>-0.005841 S</td>
<td>-0.2636 P</td>
<td>-0.1914 S</td>
<td>-0.2075 S</td>
</tr>
<tr>
<td>antipsychotic dosage (risperidone index, n=72)</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
<td>n.s.</td>
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<td>CGI-O</td>
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P = Pearson’s r; S = Spearman’s r

**Fig. 2.** Mean total ISMI scores according to the levels of education.

**Fig. 3.** Mean total DAI-10 scores according to the levels of education.
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Levels of self-stigma and current adherence to treatment in relation to discontinuation of medication in the past

When comparing the levels of self-stigma as assessed with the ISMI between patients who had discontinued their medication in the past with those who had not, no statistically significant difference between the two subgroups was observed.

When comparing the levels of self-stigma determined by the ISMI and current adherence determined with the DAI-10 between patients who had discontinued their medication in the past with those who had not, no statistically significant difference between the two subgroups was observed (Table 2).

Correlation between self-stigma and demographic and clinical data

There was no significant correlation between the levels of self-stigma expressed by the total ISMI scores and age, age of illness onset, number of hospitalizations, number of outpatient psychiatrists, severity of illness assessed by both psychiatrists and patients themselves, and antipsychotic or anxiolytic dosages. However, self-stigma did significantly negatively correlate with adherence to treatment and there was also a positive correlation with antidepressant dosage. That is, the higher was the level of self-stigma level, the lower was the patient’s adherence to treatment (Figure 5).

Correlation between current levels of adherence and demographic and clinical data

The levels of adherence as assessed with the DAI-10 questionnaire were statistically significantly negatively correlated with only the total ISMI scores (Table 3).

DISCUSSION

The study comprising 74 psychiatric outpatients with schizophrenia spectrum disorders assessed the relationships between self-stigma, current adherence to treatment, voluntary discontinuation of medication and selected demographic and clinical data.

The results suggest that as far as self-stigma is concerned, no significant role is played by a family history of mental disorder, gender, partnership status, education and subjective or objective assessment of current severity of the condition. The finding is inconsistent with those reported by some other authors. In a study by Girma et al. (2013) using the ISMI scale, for instance, women showed significantly higher self-stigma than men and the level decreased with higher education. Similarly, Mosanya et al. (2013) found an inverse association between the levels of education and self-stigma. However, a study by Yen et al. (2005) failed to confirm the relationship between gender, age and self-stigma. Such contradictory results may be attributable to different diagnostic spectra in the studies (with only the study by Mosanya et al. (2013) having a diagnostic spectrum similar to that in the present study), as well as different self-stigma assessment instruments and socio-economic and cultural settings. Our results are consistent with those in a systematic review and meta-analysis of 127 articles on stigma and self-stigma in mainly developed countries (Livingston & Boyd 2010) that failed to show a statistically significant relationship between demographic factors and self-stigma.

In the present study, the levels of self-stigma were unrelated to admitted discontinuation of medication in the past. However, the severity of self-stigma is statistically significantly correlated with the rate of current adherence to treatment and antidepressant dosage. The present study showed no association between the levels of self-stigma and severity of the condition as assessed.
by either psychiatrists or patients. The relationship between psychiatric symptom severity and the levels of self-stigma was reported in a review and meta-analysis by Livingston and Boyd (2010). In their study of inpatients, Ociskova et al. (2014) found a statistically significant correlation between the degree of anxiety symptoms and self-stigma in patients with anxiety disorders. The present study, however, was concerned with well-controlled psychosis in patients having low objective as well as subjective CGI scores, not allowing adequate assessment of the relationship between severity of the condition and self-stigma. An important question is whether the level of self-stigma is stable or varies over time, depending on how well one's mental condition is controlled. However, this could not be answered by the present cross-sectional study as data were not collected from patients with acute illness.

In the present study, current adherence to treatment was unrelated to gender, achieved education levels (this particular association was on the border of statistical significance) or partnership status. Similarly, there was no association with patient age, number of hospitalizations, number of visited psychiatrists or medication dosage. This was not true in other studies. In a study of patients with panic disorder, Grilo et al. (1998) found an association between education and adherence to treatment; patients having lower education being less adherent to their treatment. However, this may be attributable to the different diagnosis as well as lower number of participants and different assessment instruments.

Matas et al. (1992) stated that noncompliant patients were more likely to be single. The present study failed to confirm an association between adherence and partnership status. This may be due to different patient populations as unlike our study of schizophrenic patients, Matas et al. (1992) also included those with neurotic spectrum and bipolar disorders.

The most important finding in the present study was a significant correlation between adherence and self-stigma. The more self-stigmatized is a patient, the lower is his or her adherence to treatment. This is consistent with results published by Sirey et al. (2001) who examined treatment discontinuation in outpatients with depression and found that better adherence may be predicted by lower levels of perceived stigma.

Discontinuation of medication by their own will was equally admitted by men and women. This is consistent with other authors’ findings (Bulloch and Patten 2010). The present study found a weak association between discontinuation of psychoactive drugs and education levels despite an apparent trend towards medication being less frequently discontinued by more educated patients. It also seems that having a partner may not protect against discontinuation of medication. In the present study, discontinuation of medication in the past was not linked to either current severity of the condition or current adherence to therapy.

One possible limitation of the study is the fact that data were obtained using self-administered questionnaires and thus, with the exception of demographic data, objective CGI scores and medication dosage, the data could have been modified by variations in the patients’ motivation. The questionnaire responses could have been influenced by the patients’ relationship to their physicians, efforts not to disappoint them and to be seen in a better light. As many as 18% of the approached patients did not fill out the questionnaires or only partly completed them. Thus, such insufficient data on their self-stigma, adherence and discontinued medication in the past could not be included in the overall results. Although there were no differences in demographic or clinical data between these dropouts and the remaining participants it may be this subgroup of patients that has significant problems with adherence and discontinuation of medication.

Another limitation seems to be the variety of diagnoses in the schizophrenia spectrum and unequal distribution of cases with the same disorders. Moreover, different types of medication were not taken into consideration. Important limitations are the small size of the group and, last but not least, the fact that a standardized diagnostic interview was not used.

The results are cross-sectional and cannot capture the possible dynamics in mental status changes. There is no information about the stability of self-stigma over time; similarly, adherence may alter with changes in the status.

CONCLUSION

Adherence to treatment is one of the most important prerequisites for successful therapy. Adherence may be enhanced through better motivation and education of patients on the necessity of adhering to treatment recommendations and the consequences of non-adherent behavior. Important factors in adherence also seem to be patients’ stigmatization and self-stigma. If these findings are confirmed by further research, adherence may be increased by promising self-stigma-reducing strategies performed by systematic psychoeducation of patients or as a part of psychotherapeutic counseling.

REFERENCES


