

## ANTIPSYCHOTICS SIDE EFFECTS' INFLUENCE ON STIGMA OF MENTAL ILLNESS: FOCUS GROUP STUDY RESULTS

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### SUMMARY

**Background:** Little research was done on the influence of antipsychotics' side effects on stigma of mental illness. An overview of studies shows that people with mental illness state that because of medication side effects they feel discriminated in the field of employment, observe worsening of family relations and tend to skip or discontinue their regular medication. It is difficult to discriminate between stigmatizing effects of antipsychotics and other stigma related factors such as illness symptoms.

**Subjects and methods:** A focus group of ten patients with schizophrenia or schizoaffective disorder with severe and remitting mental illness treated with antipsychotic medication was conducted to obtain their personal views on how side effects of antipsychotic drugs affect their everyday lives and contribute to the stigmatization because of mental illness.

**Results:** The patients felt most stigmatized in areas of employment and occupation. They repeatedly skipped or discontinued regular medication due to side effects. Their families supported them throughout treatment and recovery despite problems associated with psychotropic medication.

**Conclusion:** Medication induced stigma affects patients' lives in substantial ways and therefore merits further research, part of which is the patients' personal experience.

**Key words:** stigma - side effects – schizophrenia – antipsychotics - focus group

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### INTRODUCTION

There was little research done on the influence of antipsychotics on stigma of mental illness. It is difficult to discriminate between stigmatizing effects of antipsychotics and other stigma related factors such as illness symptoms as stated in a review article by Sajatovic and Jenkins (2007). The risk of acute extrapyramidal symptoms, weight gain, sedation, antimuscarinic symptoms, postural hypotension and seizures are the most common side effects affecting patients' everyday living in classical and atypical antipsychotics. Relative risks of specific adverse effects between atypical and conventional antipsychotics are largely meaningless. Rather, comparisons should be made between specific atypical and specific conventional drugs (Haddad & Sharma 2007). When

substituting classical antipsychotics for atypical ones, 70% of patients reported improvement in severity of side effects, yet among these, 90% still complained of weight gain, salivation and drowsiness (Jenkins et al. 2005). Drug attitudes were no different between patients taking first- or second-generation antipsychotics or clozapine (Freudenreich et al. 2004). The illness may seem incurable because of persistent and visible side effects of classical antipsychotics (Tandon & Jibson 2002). Side effects and stigma of being treated with psychotropic medication are among the main obstacles to medication compliance (Hudson, Owen, Thrush, Han, Pyne, Thapa and Sullivan 2004). Stigma because of antipsychotic medication was divided into the categories of unwanted illness disclosure, work performance impairment, family relationship disruption and

treatment non-compliance by Lee, Chiu, Tsang, Chui and Kleinman (2002). Their research implemented qualitative analysis with focus groups and quantitative research with 320 patients with schizophrenia. 48% of patients reported of medication induced stigma. Medication induced stigma is one of the major obstacles to employment (Marwaha & Johnson 2004). The influence of side effects induced stigma on family relationships is confirmed by the study of Rudge and Morse (2004). Jenkins and Carpenter-Song (2006) thus speak of recovery without cure and stigma despite recovery. Psychosocial consequences of medication side effects include a sense of demoralization, physical discomfort and being the target of substantial social stigma and are so intolerable that patient may discontinue the treatment even if it is effective (Ruetsch, Viala, Bardou, Martin, Vacheron 2005). It is proven that the general public opinion about schizophrenia is that treatment with medication and support helps patients (Thompson et al. 2002). Recovery in mental illness nevertheless is a subjective process, which involves sacrifice of physical fitness for remission of symptoms. The process of recovery for patients is an enduring struggle which includes suppression of symptoms with medication and coping with its side effects and depends strongly on the quality of social interactions (Bebbington & Kuipers 1994). Recovery is a personal experience which is revealed by personal testimonies obtainable through qualitative research. Focus groups are commonly used as a qualitative research method in sociology and they give access to research participants who find face to face interaction intimidating, which is often the case with patients with schizophrenia. Focus groups create a safe atmosphere helpful in facilitating statements about unpleasant subjects such as stigma (Steward & Shamdasani 1994). The role of the researcher is thus reduced. The group elicits responses that reflect social reality of the participants (Krüger 1994). Focus groups were chosen as an appropriate method for stigma research (Schulze & Angermeyer 2003).

The aim of the research was to obtain patients' personal experience about medication induced stigma.

## SUBJECTS AND METHODS

In the Psychiatric Hospital Ljubljana we conducted a focus group discussion with ten patients with schizophrenia.

We used a semi-structured focus group posing open ended questions to ten inpatients diagnosed with schizophrenia or schizoaffective disorder, 4 women and 6 men aged from 30-61 years. All of the patients were to be discharged in a few days, which ascertained absence of acute psychotic symptoms. All of them had symptoms of severe and remitting mental illness and were treated with antipsychotic medication. The questionnaire of the Lee et al. study (2002) was used, with questions about side effects' influence on illness disclosure, work performance, family relationships and treatment adherence. The group was conducted by psychiatrists. An audio tape-recording was used for later analysis with patients' consent. The research was approved by the Hospital Ethical Committee.

## RESULTS

Five patients confirmed that other people perceived them as lazy and that their illness was disclosed because of coordination problems due to side effects of medication. One of them said that he was accused of just pretending. Three of them were mistaken to have addiction problems because of antipsychotic drugs and one of which was also advised to be treated in a rehabilitation clinic for illicit drug abusers. The grandmother of another patient was inquired about her granddaughters' supposed addiction. One patient was accused and harassed by a policeman for allegedly consuming marihuana. One of the patients was ridiculed because of her awkward gait.

Employment and occupational functioning was impaired in one case to the degree of being fired and in the other to the rejection of employment, although it remains unclear whether also psychiatric symptoms were involved in these consequences. Three other patients were complaining about flight of ideas, lack of concentration, tiredness and muscular rigidity manifested as clumsiness. A vivid description of the work situation was the following: 'Being in a

bad mood as it is, because I know I do not work well enough because of medication and then somebody says something to me and I go completely mad.'

Only two patients reported of criticism from close relatives, one because of staying in bed for too long, the other for his clumsiness. Four patients spoke of family compassion and understanding. A patient who broke an egg due to bad tactile sense in her hands was not reproached by her parents. The others did not mention family relations.

Due to side effects seven participants admitted to either reducing the dose or skipping their regular medication. They did so out of their own choosing (six) or after consulting their psychiatrist (one). Four said to have increased their dosage, but it turned out that they were talking about anticholinergic, not antipsychotic drugs.

Three patients did not distinguish well between side effects and illness symptoms.

## DISCUSSION

The discussion with the patients with schizophrenia showed that most patients suffering from stigma due to side effects have problems with employment and occupation and tend to skip or discontinue medication. In the workplace they felt discriminated against and suffered from impairment of their work performance perceived by themselves and others. The above is in concordance with studies by Hudson, Owen, Thrush, Han, Pyne, Thapa and Sullivan (2004), Lee, Chiu, Tsang, Chui and Kleinman (2002) (except in regard to family relations) and Marwaha and Johnson (2004). The patients' families appear to tolerate their problems and limitations. It often remained unclear whether problems arose from side effects or illness symptoms, which is confirmed by Sajatovic and Jenkins (2007). The study presented has shown the value of exploring the patients' views on medication induced stigma. The first hand information is an essential step in combating stigma and discrimination of mental illness also because their involvement mobilizes empowerment and stigma coping skills.

## CONCLUSION

People with mental illness suffer from medication induced stigma and this affects their lives in substantial ways. Therefore this field merits further research.

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