

Cognition, Adherence and Stigma in Schizophrenia

The COAST Study

AKADEMISK AVHANDLING

som för avläggande av medicine doktorexamen vid Sahlgrenska Akademien vid Göteborgs universitet kommer att offentligt försvaras i hörsal Arvid Carlsson, Academicum, Medicinaregatan 3, Göteborg, fredagen den 6 februari 2015 kl 9.00

av

Cecilia Brain

Leg. läkare

Fakultetsopponent:

Professor Martin Lambert

Department of Psychiatry and Psychotherapy

University Medical Center Hamburg-Eppendorf

Centre of Psychosocial Medicine. Hamburg, Germany

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Brain, C., Sameby, B., Allerby, K., Lindström, E., Eberhard, J., Burns, T., Waern, M. Twelve months of electronic monitoring (MEMS[®]) in the Swedish COAST-study: A comparison of methods for the measurement of adherence in schizophrenia. *European Neuropsychopharmacology* 2014; 24(2): 215-222.
- II. Brain, C., Allerby, K., Sameby, B., Quinlan, P., Joas, E., Karilampi, U., Lindström, E., Eberhard, J., Burns, T., Waern, M. Drug attitude and other predictors of medication adherence in schizophrenia: 12 months of electronic monitoring (MEMS[®]) in the Swedish COAST-study. *European Neuropsychopharmacology* 2013; 23(12): 1754-1762.
- III. Brain, C., Sameby, B., Allerby, K., Quinlan, P., Joas, E., Lindström, E., Burns, T., Waern, M. Stigma, discrimination and medication adherence in schizophrenia: Results from the Swedish COAST study. *Psychiatry Research* 2014; 220(3): 811-817.
- IV. Allerby, K*, Sameby, B*, Brain, C., Joas, E., Quinlan, P., Sjöström, N., Burns, T., Waern, M. Associated stigma and burden in relatives to persons with schizophrenia: Results from the Swedish COAST study. (Submitted).
* Equal contribution

Permission to reproduce and use content from the above published articles was obtained from the publisher.



UNIVERSITY OF GOTHENBURG

Cognition, Adherence and Stigma in Schizophrenia

The COAST Study

Cecilia Brain

Department of Psychiatry and Neurochemistry
Institute of Neuroscience and Physiology
Sahlgrenska Academy at University of Gothenburg, Sweden

Schizophrenia is a serious stigmatizing illness. Antipsychotic medication is a cornerstone in treatment. Non-adherence is a predictor of poor outcome leading to relapse, poor functioning, high mortality and costs. Reported adherence rates vary (8-86%). Most adherence studies are small, short and use subjective adherence measures known to underestimate non-adherence. The overall aim of this thesis is to increase knowledge about factors related to adherence to oral antipsychotics and to stigma in a large cohort of patients with schizophrenia or schizophrenia-like psychosis, followed for one year. The specific aims are: to examine adherence to antipsychotics and to compare objective and subjective measures of adherence; to investigate predictors of adherence; to explore stigma and discrimination and to test for potential associations between a) different types of stigma and b) stigma and adherence; to study stigma experiences and the relationship between associated stigma and burden in relatives to persons with schizophrenia.

Adherence was monitored for a year in 117 outpatients at Sahlgrenska University Hospital, Gothenburg, Sweden. Adherence was determined by the Medication Event Monitoring System (MEMS[®]), considered the reference standard, pill count, a composite measure of plasma levels and adherence to lab visits, and patient, staff, psychiatrist and close informant ratings. Symptom burden, insight, cognition, psychosocial function (PSP) and side effects were rated (n=112). Experiences of stigma (n=111) and drug attitude (using the Drug Attitude Inventory, DAI-10) of patients (n=112) and informants (n=65), as well as burden in relatives (n=65) were assessed.

Non-adherence (MEMS[®] adherence \leq 0.80) was observed in 27% of the patients. In *Study I* MEMS[®] adherence was highly correlated with pill count but very poorly correlated with the plasma level measure. In *Study II* low patient-rated DAI-10 scores and poor function emerged as predictors of non-adherence. Positive symptom burden, psychiatric side effects, lack of insight and low DAI-10 informant scores also predicted non-adherence. No association between stigma and adherence could be shown in *Study III*. Almost two-thirds of the patients reported discrimination in social relationships and “anticipated stigma”. One-half felt discriminated against by mental health staff. In *Study IV* a fifth of the relatives avoided situations that might elicit stigma, but there was no association between experienced or anticipated stigma and burden. Stigma impact regarding the relatives’ personal quality of life was associated with overall burden.

In conclusion, structured pill count might be a useful clinical tool to objectively follow adherence. The large discrepancy between MEMS[®] and the plasma level measure needs further study. Positive drug attitude in combination with good psychosocial functioning emerged as predictors of MEMS[®] monitored adherence. Associations were found neither between stigma and adherence nor the relatives’ stigma and burden, and both phenomena need to be investigated further.

Keywords: schizophrenia, adherence, Medication Event Monitoring System, antipsychotics, pill count, drug attitude, stigma, discrimination, relatives’ burden.

Correspondence: cecilia.brain@neuro.gu.se

ISBN (print): 978-91-628-9084-1

ISBN (epub): 978-91-628-9085-8

<http://hdl.handle.net/2077/37525>