LIVING WITH BIPOLAR DISORDER

The experiences of the persons affected and their family members, and the outcomes of educational interventions

Akademisk avhandling

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This thesis is based on the following papers:

- I. Jönsson P.D., Wijk H., Skärsäter I. & Danielson E. (2008). Persons living with bipolar disorder their view of the illness and the future. *Issues in Mental Health Nursing*, 29(11), 1217-1236.
- II. Jönsson P.D., Skärsäter I., Wijk H. & Danielson E. (2010). The experience of living with a family member with bipolar disorder. *International Journal of Mental Health Nursing (In press)*
- III. Jönsson P.D., Danielson E., Wijk H. & Skärsäter I.
 Outcomes of an educational intervention for persons with bipolar disorder A longitudinal and comparative two-year follow-up study. (Submitted)
- IV. Jönsson P.D., Wijk H., Danielson E. & Skärsäter I. Outcomes of an educational intervention for the family of the person with bipolar disorder: a two-year follow-up study. Journal of Psychiatric and Mental Health Nursing (Accepted)

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Abstract:

Bipolar disorder has considerable consequences for the daily life and functioning of the person affected and their family. The aim of this study was to describe the experience of living with bipolar disorder from the view of the person affected and their family. A further aim was to analyze the outcomes of educational interventions for persons with the illness and their family members in outpatient mental health care.

In Papers I and II, qualitative interviews were conducted with persons diagnosed with bipolar disorder (n=18) and family members (n=17) focusing on their experiences of life with the illness. In Papers III and IV the outcomes of educational interventions for those affected (n=32) and the families (n=34) were followed-up and analyzed. Paper III included a comparative group (n=15) of persons with the illness only receiving standard treatment. Data were collected using a semi-structured interview (III) and self-assessment instruments (III-IV) on five occasions, starting before the intervention and ending at the two-year follow-up. Content analysis was applied to the qualitative studies, whereas descriptive and non-parametric statistical methods were used for the quantitative studies. The educational intervention was an existing health care intervention in a unit in outpatient mental health care services consisting of ten group-sessions with different topics related to living with bipolar disorder which the group discussed and reflected on. It is based on the assumption that communication, collaboration and discussion in these groups create interaction that facilitate development of knowledge about and capacity to manage living with the illness.

The results of this thesis showed that the whole lives of the family and the member affected were influenced. The process of integrating the illness challenged their pre-understanding, requiring reconsideration of self among the persons affected and confirmation of the correctness of the families' experiences. Uncertainty among persons with the illness concerning their own capacity and the limited life associated with the illness influenced their view of the future. The younger adults avoided planning or hoping for the future, and without hope of improvement it sometimes felt hard to continue. The families were strongly committed to the care for the member with the illness, but felt engaged in a lonely and burdensome struggle that diminished their chances of a normal life of their own. Hope for the future, sufficient social functioning and feeling part of society was prerequisites for a manageable life for these people. The educational interventions gave them opportunity to interact and learn together with mental healthcare professional and other people within a constructive environment. The outcomes of the interventions showed that both persons with bipolar disorder and the family members increased their self-management ability as a result of their developed knowledge and their ability to meet the daily social concerns and stresses related to living with bipolar disorder improved.

This thesis contributes increased knowledge concerning what it means to live with bipolar disorder in the long-term and emphasis the importance of educational interventions with a person-centred view for person affected and family members developing their capacity to manage life. The overall support from mental health care has to be further developed and designed to meet all the specific and different needs of those persons and their families. To supplement the promising outcomes of the educational interventions more research is needed concerning increased self-management under different stages of the illness and life.

Keywords: adult, bipolar disorder, caring, educational intervention, family, follow-up studies, mental health services, psychiatric mental health nursing, self-management, young adult

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