

Caring Situation and Provision of Web-based Support for Young Persons who Support Family Members or Close Friends with Mental Illness

Akademisk avhandling

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This doctoral thesis is based on the following papers

- I Ali, L., Hedman Ahlström, B., Krevers, B., & Skärsäter, I. (2012). Daily life for young adults who care for a person with mental illness: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 7, 610-617.
- II Ali, L., Krevers, B., Skärsäter, I. Caring Situation, Health, Self-efficacy, and Stress in young informal carers of family and friends with mental illness. *Resubmitted*
- III Ali, L., Hedman Ahlström, B., Krevers, B., Sjöström, N., Skärsäter, I. Support for young informal carers of persons with mental illness: a mixed-method study. *Accepted in Issues of Mental Health Nursing*.
- IV Ali, L., Krevers, B., Sjöström, N., Skärsäter, I. Effectiveness of web-based versus folder support interventions for young informal carers of persons with mental illness: a randomized controlled trial. *Submitted*

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CARING SITUATION AND PROVISION OF WEB-BASED SUPPORT FOR YOUNG PERSONS WHO SUPPORT FAMILY MEMBERS OR CLOSE FRIENDS WITH MENTAL ILLNESS

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Abstract

Changes in psychiatric health care and increased reliance on outpatient care have resulted in the transfer of responsibility for care from psychiatric services to social networks. Young persons therefore often take responsibility during their own sensitive phase of emerging adulthood for the care of a loved one who suffers from mental illness.

The overall aim of this study was to learn how young persons who provide care and support to a person with mental illness handle their everyday lives. This study also aimed to evaluate web-based versus folder support for these young informal carers. The papers in this thesis use qualitative descriptive (I), comparative (II), mixed methods (III), and experimental (IV) design approaches. Participants were recruited twice: first, 12 participants were recruited for the qualitative papers and interviewed; then 241 participants were included in the interventions and sent self-administered questionnaires by email or the regular postal service at the start of the intervention (T_1), after 4 months (T_2), and after 8 months (T_3) during 2010 and 2011. Young informal carers (YIC) managed their everyday lives and unexpected stressors from their perceived responsibility for the supported person by relying on their own abilities and their social networks and by maintaining a constant state of readiness in case something should happen to the supported person. Supporting a person in the family can have higher positive subjective value than supporting a friend. Although friends perceived that they received more support. They often did not share their situation with others and felt that others did not understand what they were going through; even when YIC did share their burden with their social networks, they felt either that they were ignored or that others did not know how to act or what to say. YIC often experienced a lack of appropriate, available, and serious professional support. They thought that support from professionals might improve their caring situation and that it might ease their burden if the person with mental illness had more professional care and support.

Baseline stress levels were high in both intervention groups (web-based support versus informational folder), but decreased in the folder group. The folder group showed more improvement in their caring situation than the web group, and improvements in general self-efficacy, well-being, and quality of life. The web group also showed improved well-being. Non-significant differences between the groups indicate that each intervention could be useful depending upon the individual's preference. This highlights the importance of adopting a person-centred approach to offer young persons the appropriate support.

Keywords: informal carers, family, friends, mental health, support, young persons