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Living with heart failure: effects of an educational programme on patients and family members

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ABSTRACT

Chronic heart failure (CHF) is a syndrome with various underlying causes and when an individual is diagnosed with CHF it affects daily life of both him/her and family members. An educational programme may have the capability to increase the knowledge and understanding of family members and improve their possibility to support the patient with CHF.

In **paper I** the aim was to investigate perceived loneliness and social support in 149 patients with CHF and whether there was an association with gender, age, health care utilization and mortality. Loneliness was reported by 20% of the patients, who were younger and more often women. Those who perceived loneliness had fewer social contacts and emotional contacts and were less satisfied with close relationships and available social contacts. Despite not having more severe CHF, those feeling loneliness had more days in hospital and more readmissions during 12 months.

In **paper II and III** 128 family members of patients with CHF were randomly assigned to an intervention group (IG) who received a multi-professional educational programme or to a control group (CG) receiving routine ward information. Family members filled in questionnaires three times during one year. Aim of **paper II** was to investigate if disease-related knowledge increased in family members through the educational programme and if there was an effect on healthcare utilization of the patient with CHF. Findings showed that disease-specific knowledge increased significantly in both groups from baseline and at second measurement and remained at third measurement. Family members in the IG had significantly higher knowledge at second and third measurement compared to family members in the CG. Frequency of readmission or number of days hospitalised during 18 months did not differ between the groups. In **paper III** the primary aim was to investigate if quality of life (QoL), anxiety and depression were affected in family members after attending an educational programme. The secondary aim was to investigate the impact of social support, family and patient related variables and sense of coherence on changes in QoL, anxiety and depression during the study period. Findings showed no significant differences in QoL, anxiety and depression between IG and CG due to the education. Adequacy of social network and baseline measurement of anxiety and depression predicted anxiety and depression at third measurement. Baseline measurement of QoL and family member's age were predictors for QoL at third measurement. Younger family members had higher QoL.

In **paper IV** the aim was to describe family members' experiences of attending an educational programme. Eleven family members were interviewed. Three main categories emerged: "making the disease comprehensible" deals with increased knowledge among family members and thereby attaining greater understanding of the person with CHF; "increasing involvement" comprises family members' self-confidence and ability to become a resource for the ill person; "influencing family members' wellness" deals with the positive experience of meeting others in the same situation and the importance of taking care of themselves. Several of the family members would have preferred to attend the education with the person with CHF.

In conclusion Perceived loneliness in patients with CHF was most common among women and younger persons, and was associated with health care utilization, social network and support. The implemented educational programme for family members of patients with CHF seemed to have a subjectively experienced positive effect. The family members had increased knowledge, confidence and understanding of the disease, which made it easier for them to support the patient in their self-care management. The educational programme did not affect levels of QoL, anxiety and depression in family members nor health care utilization of the patients.

Keywords: Chronic heart failure, social support, educational programme, family members