

Patients with worsening chronic heart failure – Symptoms and aspects of care

A Descriptive and Interventional study

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This thesis is based on the following papers:

- I. Patel, H., Shafazand, M., Schaufelberger, M., Ekman, I. Reasons for seeking acute care in Chronic Heart Failure. *European Journal of Heart Failure* 2007;9:702-708.
- II. Falk, K, Patel, H, Swedberg, K, Ekman, I. Fatigue in patients with Chronic Heart Failure – a burden associated with emotional distress. (Submitted for publication)
- III. Patel, H., Ekman, I., Wasserman, S., Spertus, J., Persson, LO. Psychometric properties of a Swedish version of the Kansas City Cardiomyopathy Questionnaire in a Chronic Heart Failure population. (*European Journal of Cardiovascular Nursing, Epub. ahead of print 2007*).
- IV. Patel, H., Shafazand, M., Ekman, I., Höjgård, S., Swedberg, K, Schaufelberger, M. Home care as an option in worsening chronic heart failure – A pilot study with aspects on Medical safety, Quality Adjusted Life Years and Cost-Effectiveness. (Submitted for publication)



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Abstract

The aims of this thesis are to (1) explore the factors related to seeking care (Paper I), (2) describe the association between fatigue and selected symptoms (Paper II), (3) validate a method to detect the symptoms (Paper III) and (4) evaluate home care with respect to health-related quality of life (HRQL), medical safety, and cost-effectiveness in patients with worsening chronic heart failure (CHF) (Paper IV).

All studies utilise data on patients with worsened CHF who sought care at the emergency department or heart failure clinic. Semi-structured interviews were performed (Paper I), and the questionnaires were administered in the form of interviews (Papers II – IV). Eligible patients (Paper IV) were randomised either to home care (HC) or conventional care (CC). Patients in the home care group were initially treated in the emergency department or in the ward and thereafter sent home. Follow-up took place the next day by a specialist nurse and thereafter every day or every other day for 5 -7 days, determined by patient's health status. The Patients in the CC group were treated according to hospital treatment guidelines. The patients were followed up after 1, 4, 8 and 12 months in both groups.

The patients reasons for seeking emergency attention were mainly because of symptoms they experienced (58%), followed by recommendations from either relatives or caregivers (42%). Reasons for not seeking care earlier were attribution of their symptoms to the external factors, uncertainty, old age, previous unpleasant experiences with health care, and hopelessness. Only 5% could relate their current symptoms to worsening CHF. Anxiety was associated with mental fatigue, whereas depression was associated with general fatigue, a decrease in activity and reduced motivation. The Kansas City Cardiomyopathy Questionnaire (KCCQ) was valid, reliable and more responsive than the Short Form-36. Health care cost differed significantly between the HC and the CC group ($p < 0.001$ after initial intervention and $p = 0.04$ at the end of the study and $p = 0.05$ including costs from HF clinic visits, which occurred after termination of the intervention and during study period). The groups did not differ in HRQL or medical safety.

The findings from this thesis suggest that, emotional distress may influence patients' ability to identify symptoms and response for seeking care. KCCQ can be helpful in measuring symptoms in patients with CHF. HC evaluated in this study might play an important role in future care and treatment of patients with CHF. The important aspect is to identify crucial elements in individual needs and provide care accordingly. The significance of being cared for at home and factors influencing symptom reporting are discussed in this thesis.

Key words: Chronic heart failure; Deterioration; Signs and symptoms; Psychometric properties; Kansas City Cardiomyopathy Questionnaire; Quality-adjusted life years; Cost-utility analysis; emotional distress; health care costs