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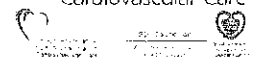
Co-Editors: **Anna Stromberg**  
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provide important knowledge for planning evidence-based nursing support for this patient group.

**Purpose:** To examine the associations between illness perceptions and depression in patients with chronic heart failure and to examine the potential mediating effect of avoidant coping behaviour.

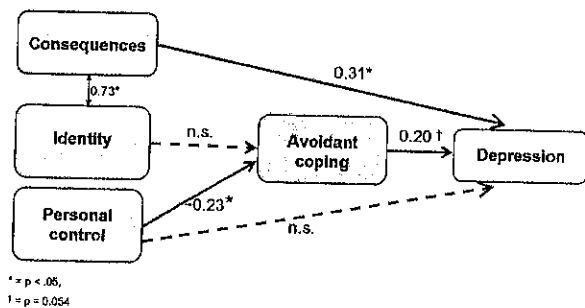
**Method:** 81 patients diagnosed with CHF in NYHA-class II and III were recruited from a heart failure out patient clinic. The participants filled in forms to measure illness perception (B-IPQ), coping strategies (Brief COPE), anxiety and depression (HADS).

**Results:** Univariate analysis revealed personal control ( $r = -0.259$ ,  $p < 0.05$ ), consequences ( $r = 0.499$ ,  $p < 0.01$ ), and identity ( $r = 0.475$ ,  $p < 0.01$ ), to be significant correlates of depression. In a path-analysis with avoidant coping as a mediator between illness perception and depression, the effect of personal control on depression was shown to be fully mediated by avoidant coping. Consequences, i.e. the perception of the daily impact and constraints caused by CHF, uniquely predicted depression.

**Conclusion:** The findings indicate that both illness perception and coping strategies are important components for depressive symptoms in patients with CHF. Avoidant coping may be explained by the patients' sense of his or her own lack of ability to control the condition. The findings may be implemented in systematic efforts such as patient education and coping interventions.

Figure 1

Path-analysis of domains of illness perception with avoidant coping as a mediator for depression



PI53

### Quality of counselling of patients with cardiac sarcoidosis

R Turpeinen,<sup>1</sup> L Kalam-Salminen,<sup>2</sup> H Lampi,<sup>2</sup> S Kaivos,<sup>3</sup> H Kyngas<sup>4</sup> and M Kaariainen<sup>4</sup>

<sup>1</sup>Health Centre of City of Helsinki, Helsinki, Finland <sup>2</sup>Helsinki Metropolia University of Applied Sciences, Helsinki, Finland <sup>3</sup>Finnish Heart Association, Helsinki, Finland <sup>4</sup>University of Oulu, Oulu, Finland

Cardiac sarcoidosis (CS) is a rare disease present throughout the world. Patient counselling requires nursing staff to

be familiar with the disease. Research data on the counselling of patients with rare diseases is scarce. The aim of this cross-sectional study was to describe the quality of counselling of Finnish patients with CS.

Data were collected in 2011 by postal survey from all 51 patients with CS in the Finnish Heart Association's register, using a Counselling Quality Instrument modified for this study (© Kääriäinen 2009). The instrument used a 5-point Likert scale ( $\leq 2.49$  = poor, 2.50–3.49 = satisfactory and 3.5–5 = good) and included four quality areas: counselling resources, sufficiency, practical implementation and effects. Forty patients (71.4%) responded. The numerical data were analysed with PASW Statistics 18 software and the qualitative data by content analysis.

Most patients found counselling resources good (mean 3.61, SD 1.27). Counselling sufficiency was described in three dimensions: impact of illness on daily activities and coping (mean 2.25, SD 1.01), examinations and treatment (mean 2.43, SD 1.02), and restrictions due to illness (mean 2.04, SD 0.97). The counselling sufficiency dimensions were considered poor. Practical implementation was also divided into three dimensions: patient-centredness (mean 2.64, SD 1.26), interaction (mean 3.45, SD 1.33) and target-orientedness (mean 2.42, SD 1.28). Counselling patient-centredness and interaction were considered satisfactory but target-orientedness poor. Impacts of counselling were considered satisfactory (mean 3.10, SD 1.28). The patients stated that counselling should be developed by increasing nursing staff awareness of CS and its impact on daily life. They felt the counselling was fragmented, routine and nursing staff-oriented. Patients wanted counselling to be appropriately timed, individual and have continuity.

These findings indicate that the counselling was not always sufficient. The counselling of patients with rare cardiac conditions must be developed to ensure patients are on an equal footing with those with major public health conditions. Further research on rare diseases and patients' counselling experiences is required. Peer support and counselling material should also be developed.

To improve the quality of treatment and counselling of patients with rare diseases, the European Council has issued a recommendation that all EU member states introduce national rare disease programmes by the end of 2013. The recommendation emphasises EU-internal collaboration and the importance of Centres of Expertise.

PI54

### The value of an exercise advice in heart failure patients

E Vellone,<sup>1</sup> T Jaarsma,<sup>2</sup> A Cocchieri,<sup>1</sup> O Chiala,<sup>1</sup> R Fida,<sup>3</sup> R Rocco<sup>4</sup> and R Alvaro<sup>1</sup>

<sup>1</sup>University Tor Vergata, School of Nursing, Rome, Italy <sup>2</sup>Linköping University, Department of Social and Welfare Studies, Linköping, Sweden <sup>3</sup>Sapienza University of Rome, Rome, Italy <sup>4</sup>Center of Excellence for Nursing Scholarship, Rome, Italy

**Purpose:** Exercise is an important non-pharmacological intervention that can improve outcomes in Heart Failure patients (HF). However, in HF patients the actual performance to exercise is often low due to factors that can be related to, for example, patient characteristics, clinical variables and the health care system. The purpose of this study was to examine the frequency of exercise of HF patients in Italy and to explore the relationship between exercise and sociodemographic and clinical variables and the advice on exercise given by health care providers.

**Methods:** In total 1192 patients living in 40 provinces across Italy (mean age  $72 \pm 11$ , 58% female, 76% in NYHA class II and III) were enrolled in the study. Data were collected during routine clinic or hospital visits with a structured questionnaire and from the medical charts and included age, education, illness duration, ejection fraction and hemoglobin level. Cognitive impairment was measured by the Mini Mental State Examination (MMSE) and comorbidity by Charlson Comorbidity Index (CCI). Data on the exercise advice and the amount of exercise was collected by interview. Descriptive statistics, spearman's correlation coefficient and a linear regression model were used to analyze the data.

**Results:** In total 43% of the patients reported to be advised to do only a minimal or no exercise and 52% of the patients reported to exercise less than 30 minutes the last week. The frequency of self reported exercise in the last week was significantly correlated to patients' age ( $r = -.27$ ;  $p < .01$ ), education ( $r = .21$ ,  $p < .01$ ), illness duration ( $r = -.08$ ;  $p < .01$ ), NYHA class ( $r = .23$ ;  $p < .01$ ), ejection fraction ( $r = .15$ ;  $p < .01$ ), hemoglobin level ( $r = .08$ ;  $p < .05$ ), MMSE ( $r = -.23$ ;  $p < .01$ ) and CCI scores ( $r = -.17$ ;  $p < .01$ ). The frequency of self reported exercise in the last week was strongly related to the exercise advice ( $r = .42$ ;  $p < .01$ ). When these variables were entered into a regression model, only patient's age ( $\beta = -.15$ ) and exercise advice ( $\beta = .31$ ) were independently related to exercise in the last week.

**Conclusions:** The advice of the health care provider related to exercise was, together with age, an important variable related to the exercise performed, even when corrected for clinical and demographic variables. This implies that clinicians should take the responsibility and take the first step to give HF patients concrete advice on exercise.

**Purpose:** Relatives play a crucial role for patients in connection to heart or lung transplantation. Little is known about relatives' experiences of information and support in these situations. The aim was to illuminate important events on the received or lack of information and support experienced by close relatives to newly listed heart or lung transplant patients.

**Methods:** The critical incident technique was used. Incidents were collected via interviews with 16 relatives (28-73 years) to heart or lung transplant patients from one transplant centre in Sweden. The interview took place when the patients had been on the waiting list between two and four weeks. The relatives were chosen by the patients themselves.

**Results:** In all, 385 important incidents, both positive and negative, were identified and divided into two main areas. The first "Experiencing information and support" were associated with satisfying needs, dissatisfaction with the healthcare system, support to the patients and perception of the social network's role. The second "Reflecting upon information and support" describes how relatives found strength and that they were not comfortable with their own feelings.

The relatives received information from and communicated with the multi-disciplinary team at the transplant centre. However, before acceptance for transplantation the relatives only received partial information. Internet was used as an alternative source of information but it was difficult to handle the mass of information. The relatives often felt support from other relatives and friends while support from public organizations sometimes was bending. Despite information all relatives felt uncertainty regarding the future.

**Conclusion:** The results indicate that the information and support needed and received by relatives varies and more attention should be paid to them. The transplant team, other healthcare professionals and other institutions must better understand the experiences, resources and challenges faced by relatives to heart or lung transplant patients. An important implication is to enhance the knowledge about transplant patients in other institutions by open up for cooperation. It is important to promote information and support from previously transplanted and their families and healthcare professionals to develop support measures to relatives in view of the chronic condition of the patient and with a holistic approach. Internet may in greater degree be efficiently exploited for the provision of evidence-based directed information, practical and psychosocial service to relatives in need of information and support.

## PI55

### Close relatives experience of information and support when the patient recently was accepted for the waiting list for heart or lung transplantation

B Ivarsson,<sup>1</sup> B Ekmehag<sup>1</sup> and T Sjöberg<sup>1</sup>

<sup>1</sup>Lund University, Skane University Hospital, Clinical Sciences, Lund, Sweden