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**Linköping University Post Print**

N.B.: When citing this work, cite the original article.

Original Publication:

Susanna Ågren, Lorraine Evangelista, Carina Hjelm and Anna Strömberg, Dyads affected by chronic heart failure: a randomised study evaluating effects of education and psychosocial support to patients and their partners, 2012, Journal of Cardiac Failure, (18), 5, 359-366.

<http://dx.doi.org/10.1016/j.cardfail.2012.01.014>

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Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-56231>

# **Dyads affected by chronic heart failure – a randomized study evaluating effects of education and psychosocial support on patients and their partners**

*Short title: Education and psychosocial support to patients with heart failure and their partners*

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The study was financially supported by grants from the Linköping University, Swedish Research Council, Swedish Institute for Health Sciences, Heart and Lung Foundation, Heart and Lung Disease National Association, Lions Research Foundation.

**Abstract (193 words)**

**Background:** Chronic heart failure (CHF) influence daily life and may cause great suffering for both patients and their partners. Therefore we aimed to evaluate the effects of an integrated dyad care program with education and psychosocial support to patients with CHF and their partners 3-months post-discharge following acute exacerbation of CHF

**Methods:** A randomised, controlled design with a follow up assessment after 3 months was used. The dyads in the control group received usual care. The experimental group participated in an integrated intervention, delivered in three modules through nurse-led face-to-face counselling, a computer-based education and other written teaching materials to assist dyads develop self-care and problem-solving skills.

**Results:** The intervention improved perceived control ( $P < 0.05$ ) in patients, but not in partners. There were no other significant differences between the groups with regard to dyads' health related quality of life and depressive symptoms, patients' self-care behaviors and partners' experiences of caregiver burden.

**CONCLUSION:** Education that focuses on problem-solving and psychosocial support provided after HF exacerbation appears to be effective in enhancing patients' levels of perceived control. More frequent professional contact and ongoing skills training may be necessary to impact caregiver outcomes and warrants further research.

**Keywords:** heart failure, family, perceived control, health related quality of life

## **Introduction**

Patients with chronic heart failure (CHF) and their partners form a large group in health care. The prevalence of symptomatic CHF is estimated at approximately 26 million individuals in the extended Europe (1). In the United States the estimated prevalence of HF is 5.7 million. HF incidence approaches 10 per 1,000 people after age 65 (2). The condition is a leading cause of hospitalization for elderly patients and prognosis is poor with half of the patients dying within 4 years after diagnosis (1). Marital quality has been found to predict survival during an 8-year follow up period (3). Patients' self-report of having a good marriage (i.e. being married to a person who provides sufficient emotional support) also led to less severe symptoms and better mental health in patients with chronic HF (3). Partners often supported patients in their different daily activities. The most prominent caregiving areas for partners were practical support such as taking care of the household, shopping, and finances (4). Spouses provided assistance and psychosocial support for more hours than other family members due to the strong emotional bonds that exists between the patient and their partner (5).

The literature is replete with studies that support that giving care to family members with chronic HF can lead to stress and exhaustion (3, 6, 7), The risk profile for negative caregiver outcomes included greater patient needs for care and cognitive impairment, more physical symptoms, and a risk for clinical depression in the caregiver (8). Burden, stress and depression have been found to be associated with the partner's situation as a caregiver and the decreased well-being of the partner can have consequences for the health of the CHF patient (9). Previous research by Luttik et al. showed that changes in the relationship of dyads affected by CHF were related to communication difficulties between the patient and the partner. Clearly, interventions to reduce the negative consequences of CHF for caregivers need to be evaluated (1, 10-13). Partners should never be ignored or made to feel like an outsider by health care providers (11, 14). Preparing partners for the caregiving role and helping them cope with the psychological consequences of living with someone with a terminal illness such as CHF was found to have an important effect on the impact of the care (15).

Unfortunately, several studies showed that patients with CHF and their partners did not feel that they received sufficient support from health care professionals and had little understanding of the CHF condition, the aim of the treatment or the prognosis (15,16). Boyd and colleagues (2004) reported that psychosocial support, patient and partner education, and

coordination of care between primary and hospital care and social services were generally poor which led to decreased health-related quality of life (HRQOL) in the dyads (17). Thus, strategies to support and strengthen the caregiving role are needed (18); even a single meeting to discuss self-care behaviors was found to stimulate important discussions between the dyads (12). Duhamel et al. (2007) showed that a nursing intervention aimed at obtaining a better understanding of each other's experiences helped alleviate both the patient and caregiver's suffering (19). Likewise, providing patients with education about CHF and its treatment, emotional counselling, close monitoring and follow-up has been shown to decrease mortality, morbidity, hospital costs, as well as improving medication adherence and enhancing HRQOL (20-24).

While several studies have been completed to examine interventions aimed at helping partners cope with the distress of managing the care of elderly patients with CHF, these studies were mostly descriptive in nature and had a small sample size. To address the gaps in current research an integrated cognitive-behavioural framework that focuses on problem solving, information acquisition, self-care management for symptoms, and emotional and social support for patient-partner dyads is therefore proposed. The specific aims of this study were to evaluate the effects of an integrated dyad care programme with education and psychosocial support to patients with CHF and their partners during a post-discharge period of 3 months after acute deterioration of CHF. Cognitive-behavioural strategies assist dyads in recognizing and modifying factors that contribute to physical and emotional distress by changing thoughts and behaviours in a positive manner and assisting dyads in solving problems related to implementing strategies for self-care (25, 26). Computer-based education has been shown to be feasible and effective in terms of improving knowledge in elderly patients with CHF (27). Our hypothesis was that a care programme that combines cognitive, psychosocial and behavioural therapy designed for patient-partner dyads can improve patient and partner outcomes.

## **Methods**

### ***Design and setting***

A randomized, controlled design with a follow up assessment after 3 months was used to evaluate the effects of the intervention. The setting was one university hospital and one county hospital in south-eastern Sweden.

### ***Sample***

The sample included “dyads” consisting of a patient and a partner as being the informal caregiver. Shared care is a dyadic process based on the assumption that each participant affects and is affected by the other (28,29). The inclusion criteria were to be a dyad consisting of a patient diagnosed with CHF based on the European Society of Cardiology guidelines (1), in NYHA class II-IV, with a partner living in the same household as the patient, and recently discharged from the hospital (i.e. 2-3 weeks) following an acute exacerbation of CHF.

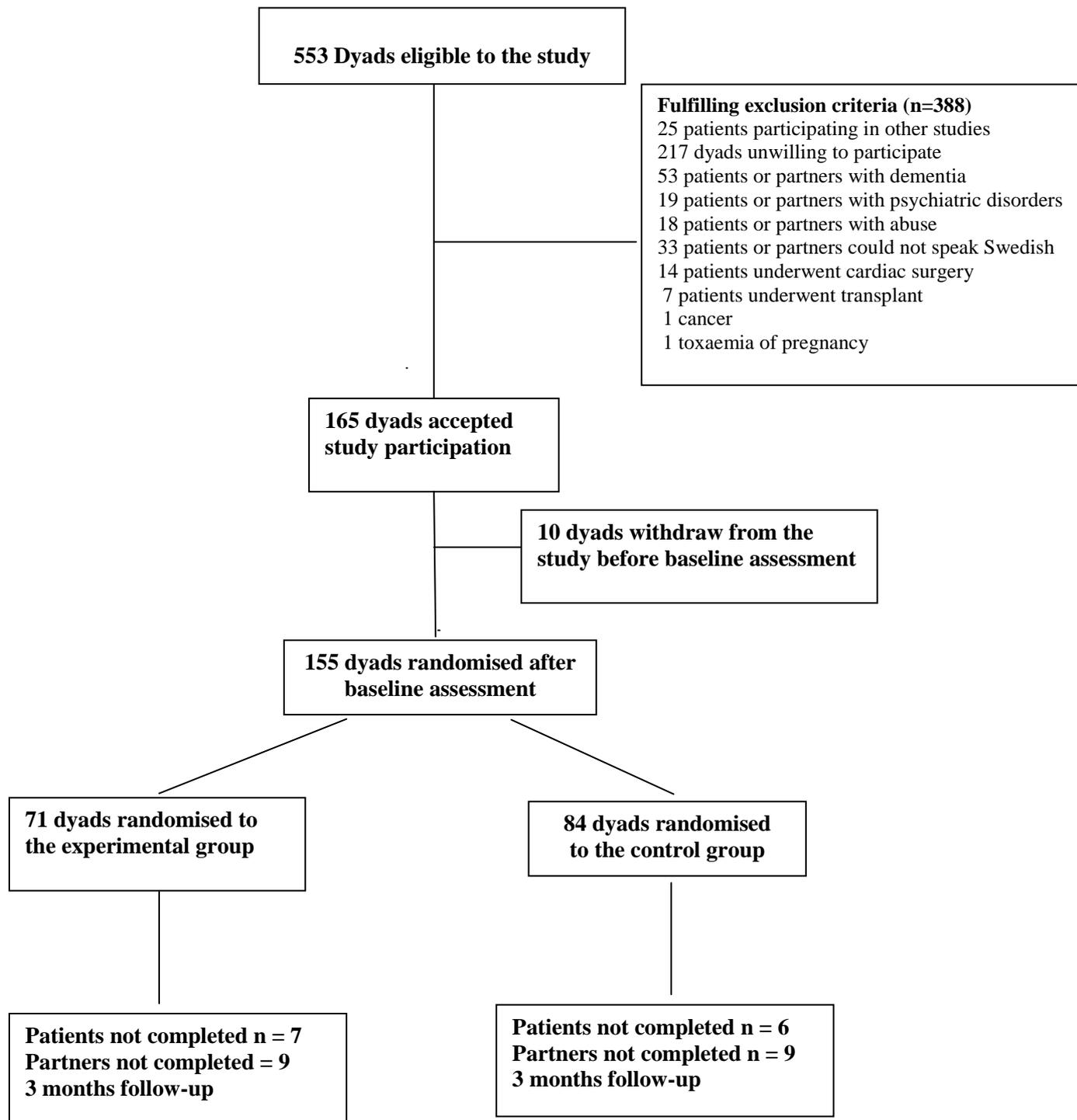
Exclusion criteria for the dyads were dementia, or other severe psychiatric illnesses, drug abuse, difficulties in understanding or reading the Swedish language, undergoing cardiac surgery including cardiac transplant or participating in other studies. A flow chart illustrating the sample process is shown in figure 1.

### ***Procedures***

The dyads were recruited between January 2005 and December 2008. Potential dyads included all patients hospitalized with CHF exacerbation at the Emergency Department and the Department of Cardiology at a university hospital and all hospitalised patients visiting a nurse-led chronic HF clinic at a county hospital. The dyads were initially informed verbally of the study through a telephone call or during a visit to the heart failure clinic. Potential patient-partner dyads interested in taking part in the study who provided written informed consent were given additional information related to the study and questionnaire-packets to complete in their own homes. Dyads that chose to participate returned the questionnaires by mail and were randomized to either the control or experimental group. The randomization code was developed using a random-number table.

### ***Ethical issues***

Throughout the study the principles outlined in the Declaration of Helsinki have been followed. Permission to carry out the study was granted from the Regional Ethical Review Board in Linköping (Dnr 03-568, Dnr M178-04). All dyads were approached in a sensitive manner and received verbal and written information about the study. Dyads that chose to participate gave written informed consent before entering the study. The dyads were assured confidentiality and that a decision to withdraw from the study would not affect their future care.



**Figure 1.** Flow chart illustrating the dyads through the clinical study

### ***Control conditions***

The dyads in the control group received care as usual including traditional care in hospital and outpatient education and support. At present the care is mainly focused on the patient's needs (24, 27). The partner is not systematically involved in the follow up focusing on education and psychosocial support.

### ***Experimental conditions***

In the experimental group, patients received usual care and treatment and in addition participated in an integrated care intervention, including psychosocial support to maintain and strengthen the person's physical and mental functions, knowledge and perceived control to make them feel involved and reduce their stress and the partners' burden. It was delivered on three sessions through nurse-led face-to-face counselling, a computer-based CD-ROM program and other written teaching materials (Table 1). The dyads were assisted by the nurse when working with the computer-based program if needed. Each session included education of CHF and development of problem solving skills to assist the dyads in recognizing and modifying factors that contribute to psychological and emotional distress. The intervention focused on changing thoughts and behaviours and implementing strategies for self-care. The first session was conducted 2 weeks after the discharge and the two remaining sessions occurred 6 and 12 weeks following discharge. The three sessions were conducted at the dyads' homes or in the heart failure clinic, depending on the preference of the dyad. Each session lasted approximately 60 minutes. After 12 weeks all the dyads received a reinforcement of the intervention including an assessment of outcomes on support and behaviour. The dyads were also offered repeated computer-based education. The dialogue guide used during the sessions included an opportunity for the dyads to discuss their mutual and individual life situation, receive information, raise questions, discuss difficulties and subjects of joy and deal around emotional and practical support and self-care. One important issue was the changing roles that arise and how to reduce the partners' overprotection if needed, the dyads' criticism of each other and how to decrease the partner's burden through support from the patient, the social network and health care professionals. The dyads were also encouraged to talk about lifestyle changes, married life, communication and prospects and learning to live with lifelong CHF. The integrated care program covered a 3 month intervention period.

**Table 1.** Content of each of the three modules utilised in the intervention

	<b>Module 1</b>	<b>Module 2</b>	<b>Module 3</b>
<b>Cognitive Component</b>	The circulatory system, definition of HF, medications and symptom management	Lifestyle modifications; diet, smoking cessation, alcohol, immunisation, regular exercise	Directing the care, relationship and sexual activities, prognosis
<b>Cognitive Outcomes</b>	Increased knowledge on the chronic HF syndrome and treatment	Increased knowledge on the rationale for lifestyle changes	Increased knowledge on chronic HF care and outcomes
<b>Support Component</b>	Introduce psychosocial support concept	Assess patient's need of support Modify caregiver behaviour	Assess partner's need of support Discuss partner's burden
<b>Support Outcomes</b>	Improved mental and physical functions	Strengthen self care behaviour	Improved mutual support Decreased partner's burden Improved control
<b>Behavioural Component</b>	Intentions, abilities and self-efficacy regarding self-care	Barriers to lifestyle modifications	Strategies to improve or maintain self-care behaviour
<b>Behavioural Outcomes</b>	Daily weighting Monitoring of	Salt and fluid restriction	Identifying life priorities and planning for the

	symptoms Flexible diuretic intake Adherence with medications	Influenza and Pneumococcal Immunisations Regular Exercise	future
<b>Teaching material</b>	Booklet 1 – basic level Flip chart	Booklet 2 – advanced level CD - ROM	Booklet 2 – advanced level CD-ROM

### *Questionnaires*

Permission to use and instructions for scoring each instrument was obtained from the appropriate publisher.

Patient and partners completed separate questionnaire packets. All questionnaires were issued to both the patient and the partner except the European Self-Care Behaviour Scale which applied only to the patients and Caregiver Burden Scale which only applied to the partners.

The follow up data will be collected at 3, 12 and 24 months. The data from the 3 month follow up is presented in this paper.

1. *Demographic data including health history* was collected using a self-administrated questionnaire identifying age, gender, education, habits like smoking, alcohol consumption and physical activity, psychosocial support and co-morbidity. NYHA-class was abstracted recorded from medical charts.
2. *Short Form (SF) - 36:* is a generic 36-item scale which evaluates health in 8 dimensions. The dimensions are weighed together in two consecutive indexes; physical component score (PCS) and mental component score (MCS). The physical part is made up of the dimensions of physical functioning, physical role functioning, bodily pain and general health and the mental part of the four dimensions of vitality, social functioning, emotional role functioning and mental health. A higher score indicates better health. The SF-36 is a well established and frequently used instrument

and has been found to have good reliability and validity. Most reliability estimates have exceeded the 0.80 level (30).

3. *Beck Depression Inventory (BDI) - II*: is a 21-question multiple-choice self-report inventory with each answer being scored on a scale value of 0 to 3. Higher total scores indicate more severe depressive symptoms. The cut off scores used were: 0–13: no depression; 14–19: mild depression; 20–28: moderate depression; and 29–63: severe depression (31,32). The instrument has been validated in Swedish. The reliability coefficient alpha showed  $>0.86$  (32).
4. *Control Attitude Scale (CAS)*: is a 4-item tool designed to measure a person's perceptions of control over their cardiovascular-related health, The CAS was also used in the partners. Perceived control is important for psychological well-being and recovery. The questions were directed at the levels of control and helplessness patients perceive and how much control and helplessness they think the patient/partner has. Response statements are scored on a scale from 1 (none) to 7 (very much). The total score range is 4 to 28, with higher scores reflecting higher levels of perceived control. (10, 33). Reliability testing across studies revealed Cronbach's alpha values for CAS ranging from 0.77 to 0.89 (33). The psychometric testing for the Swedish translation has shown reliability coefficient alpha  $>0.80$  for the patient version and 0.60 to 0.70 for the partner version (34).
5. *European Self-Care Behaviour Scale (EHFscBS)*: is a 12-item scale that utilizes a 5-point Likert scale between 1 (I completely agree) and 5 (I completely disagree) to measure self-care behaviours related to chronic HF. Overall score ranges between 12-60; lower scores indicate better self-care behaviour (35, 36). The psychometric testing for the Swedish translation has shown reliability coefficient alpha of 0.77 (36).
6. *Caregiver Burden Scale (CBS)*: is a 22-item scale that measures caregiver burden as subjectively experienced by caregivers of chronically disabled persons. Responses were scored on a scale from 1-4 (not at all, seldom, sometimes, often). The total burden index is the mean of all 22-items; higher scores indicate greater burden. The total burden index CBS score can be divided into three groups; low burden (1.00-1.99), medium burden (2.00-2.99) and high burden (3.00-4.00) (37, 38). A previous study on reliability showed high internal consistency for the five indexes found in a factor analysis with Cronbach's alpha values between 0.70 and 0.87, except for the index environment (0.53). (37).

### ***Validity and reliability***

Cronbach  $\alpha$  coefficients were calculated for all scales to evaluate internal consistency reliability in this study. Cronbach  $\alpha$  was  $> 0,7$  for all scales except CAS-family version.

### ***Data analysis***

Statistical analysis was performed using SPSS release 15.0 for Windows. Frequencies were run in order to determine the amount of missing data. Missing data was 0.7 – 8.1 % at baseline, and at 3 months it was up to 10.9 %. Missing data on SF-36 were imputed by the mean of the subscale if only one item in a subscale was missing and in the European Self-Care Behaviour Scale with score three if less than three items were missing. Missing data of the other instruments were not replaced. To examine the equality of the two groups, baseline socio-demographic and clinical characteristics were compared using chi-square or student t-tests depending on the level of measurement. Randomization should ensured equal distribution between the two groups of potentially confounding characteristics. The effect of the intervention on each of the variables of interest was evaluated at the aggregate level by a student t-test to determine if the control and experimental groups had significantly different mean scores on all variables of interest at baseline and 3 months. The mean changed scores for the control and experimental group were also compared using a student t-test. The categorization of co-morbidity, BDI, CBS for control and experimental group were compared using a chi-square test. The level for statistical significance was set to  $p < 0.05$ .

### **Results**

A total of 155 dyads were included in the study and completed baseline assessment (Figure 1). Twelve patients did not complete the assessment at the 3 month follow up and 1 patient was not alive. Eighteen partners did not complete 3 month follow up.

Clinical and demographic characteristics of the dyads are described in Table 2 and 3. The majority of the patients were men and the majority of the partners were women. New York Heart Association class III was dominant as function-class of the patients.

The intervention lasted up to 3 months and the first follow up evaluation presented in this study was carried out after 3 months. Patients in the intervention group demonstrated improved levels of perceived control after 3 months ( $P < 0.05$ ), Table 4. However, the same result was not found in the partners as their perceived control remained unchanged in both the intervention and the control group. There were no significant differences in HRQOL and

symptoms of depression in dyads, self-care behaviour in patients and caregiver burden in the partners between the control and intervention groups after 3 months of intervention, Table 4.

**Table 2:** Clinical and demographic characteristics of the patients

	<b>Control</b> (n=84)	<b>Intervention</b> (n=71)	<b>p-value</b>
<b>Age</b>			
Mean±SD	73±10	69±13	ns
<b>Gender</b>			
Men	68 (80.9 %)	49 (69.1 %)	ns
Female	16 (19.1 %)	22 (30.9 %)	ns
<b>NYHA class</b>			
II	25	24	ns
III	43	39	ns
IV	16	7	ns
<b>Type of co-morbidity</b>			
Myocardial infarction	38	24	ns
Hypertension	26	27	ns
Diabetes	10	8	ns
Stroke	8	9	ns
Lung disease	7	3	ns
<b>Medication</b>			
ACEI	76	65	ns
β-Blockers	74	62	ns
Diuretics	63	56	ns

**Table 3:** Clinical and demographic characteristics of the partners

	<b>Control</b> (n=84)	<b>Intervention</b> (n=71)	<b>ρ-value</b>
<b>Age</b>			
Mean±SD	70±10	67±12	ns
<b>Gender</b>			
Men	16 (19.1 %)	22 (30.9 %)	ns
Female	68 (80.9 %)	49 (69.1 %)	ns
<b>Type of co-morbidity</b>			
Myocardial infarction	13	8	ns
Hypertension	25	25	ns
Diabetes	4	7	ns
Stroke	4	3	ns
Lung disease	10	1	<0.05

## Discussion

To our knowledge, this is the first major randomized study to examine the effects of an intervention with education and psychosocial support for patients with CHF and their partners. Our main finding was that perceived control significantly improved in the patients. This is an important outcome since previous studies have shown that a higher level of perceived control is important to reduce psychological stress (39). However, as a result of the increased experience of control we did not find a direct improvement in the patients' mental well-being, since symptoms of depression did not decrease and the mental dimension of HRQOL did not significantly improve. The intervention lasted up to 3 months which might explain why the other variables were not yet affected. It is debatable if the dyads had started benefitting from the third session in particular at 12 weeks. Additional changes may be noted

**Table 4.** Mean difference in health related quality of life and symptoms of depression in patients and partners, self-care in patients and caregiver burden in partners between baseline and 3 months follow up. Decreased values indicate an improved health related quality of life and perceived control. Increased values indicate less depressive symptoms, improved self-care behaviour and a decreased caregiver burden.

<b>diff 0-3mån</b>		<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>p-value</b>
<b>Patients</b>	Control	76	-0.43	4.8	0.03
	<b>Perceived control</b> intervention	64	-2.2	4.5	
<b>Partners</b>	Control	75	-1.8	10.0	0.60
	<b>Perceived control</b> intervention	62	-1.0	4.7	
<b>Patients</b>	Control	59	-.5	6.35	.986
	<b>SF-36 – PCS</b> Intervention	54	-.52	7.58	
<b>Partners</b>	Control	59	.80	6.86	.744
	<b>SF-36 – PCS</b> Intervention	55	1.22	6.6	
<b>Patients</b>	Control	59	-3.09	12.48	.099
	<b>SF-36 – MCS</b> Intervention	54	.31	8.8	
<b>Partners</b>	Control	59	-2.31	9.34	.444
	<b>SF-36 – MCS</b> Intervention	55	-.95	9.62	
<b>Patients</b>	Control	32	.56	10.8	.167
	<b>BDI</b> Intervention	33	4.07	9.32	
<b>Partners</b>	Control	33	-.1	3.19	.542
	<b>BDI</b> Intervention	36	-.75	5.37	
<b>Patients</b>	Control	66	1.97	6.91	.347
	<b>Self-care behaviour</b> Intervention	60	3.08	6.27	
<b>Partners</b>	Control	73	-.25	6.55	.253
	<b>Caregiver burden</b> Intervention	62	1.13	7.36	

PCS = Physical Component Scale, MCS = Mental Component Scale, BDI = Beck Depression Inventory

during the 12 and 24 months follow up. More frequent professional contact and ongoing skills training may be necessary to impact caregiver outcomes and warrants further research.

Our hypothesis that education and psychosocial support for dyads will improve patients' care has been investigated previously in a pilot study by Dunbar et al. (2005) who found that adherence to non-pharmacological treatment in terms of dietary sodium intake was improved after a family intervention (40). Previous studies have shown that both patients and partners were worried, did not receive enough support and have reported increased burden (9, 41). Dyads affect each other with regard to HRQOL and symptoms of depression (42, 43). Partners experience more distress when the patient has a more advanced end-stage CHF (44, 45). The reason for the neutral effects of the intervention in the partners in our study may be that our group of patients, even though classified as a risk group due to their NYHA functional status and recent hospitalization for CHF, were more stable than other populations investigated (44,45). Previous studies with positive results of psychosocial and education interventions targeting patients have often included more than 50% of patients living on their own without a partner (24,46). It might be that even without the intervention the dyads found sufficient coping-strategies for supporting each other (2). Moreover, in comparison with other disease groups, there is a greater burden of caregiving in, for example, dementia and stroke patients (47,48).

Would there have been other outcomes more relevant to measure when evaluating the intervention? Most of the instruments used (SF-36, BDI, CAS, EHFscBS, and CBS) have good validity and have often been used to evaluate similar interventions. To include more items might have increased the dropout rates due to subject burden. Interviews would be an option for dyads to express themselves more in-depth, but in a large randomized sample this methodology has limitations.

The study has some limitations that need to be addressed. First, the data collection spanned almost four years. Many patients with CHF either lacked a partner who could participate in the study which was confirmed in a study by Lamura et al. (2008) or were too sick and tired to participate in the study which suggests the potential for bias in the study sample (5). However, there were no big changes in diagnostic methods or treatment or other social reforms including CHF patients and their partners during the time period of data collection. The high number of items in the questionnaire packet can be experienced as exhausting for elderly patients to complete. At the 3 month follow up, 12 patients (1 patient dead) and 18 partners had questionnaire packets with too much missing data or did not

complete the questionnaires at all. It can be expected that the frailest dyads had the most problems during data collection which may affect the generalizability of the results. Another limitation was that patients in the control group might have received education and psychosocial support that to some extent was based on the same principles as the intervention group since they received care at a heart failure clinic and some partners may have been included in that care. However, the main difference was that partners in the intervention group were always actively involved as equal to the patient since they were treated as a dyad. The intervention was built on a standardized, theory-based model (27) and adjusted based on the specific needs of each dyad. A heart failure nurse delivered the intervention. It may have been more beneficial to include a multidisciplinary team in the intervention including physiotherapists, psychologists or social workers and physicians. The intervention should perhaps also have involved group sessions giving the dyads an opportunity to share experiences with each other.

## **Conclusion**

The dyad care programme focusing on development of problem solving skills to assist the dyads in managing CHF significantly improved the level of perceived control over the heart disease in the patient group. In other aspects, such as physical and mental well-being, self-care and experienced caregiver-burden, the effects were limited both in patients and partners. However, as the intervention lasted for 3 month this short term follow up needs to be complemented by 12 and 24 months follow up that may reveal other long term effects.

## **Acknowledgement**

We thank Linköping University, the Swedish Institute for Health Science, the Swedish Research Council and the Health Sciences Centre for financial support. We also thank the partners and chronic HF patients who participated in the study, the secretaries at the department of cardiology and the department of emergency, especially Lotta Björk and Berit Anderson, and Annette Waldemar and Lillevi Nestor at the county hospital in Norrköping for support with data collection and intervention. Thanks also to Cecilia Hedenstierna for data entry and Karl Wahlin for statistical advice.

## **Disclosures**

No conflict of interest

## References

1. Dickstein K, Cohen-Solal A, Filippatos G, McMurray JJ, Ponikowski P, Poole-Wilson PA, Strömberg A et al. "ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008. *European Journal of Heart Failure* 2008;10:933-989.
2. Lloyd-Jones D, Adams R, Carnethon M, De Simone G, Ferguson B, Flegal K, et al. AHA Heart Disease and Stroke Statistics 2009. *Circulation* 2009;119: e21-e181.
3. Rohrbaugh MJ, Shoham V, Coyne JC. Effect of marital quality on eight-year survival of patients with heart failure. *American Journal of Cardiology* 2006;98:1069-1072.
4. Luttik ML, Jaarsma T, Tijssen JG, van Veldhuisen DJ, Sanderman R. The objective burden in partners of heart failure patients; development and initial validation of the Dutch Objective Burden Inventory. *European Journal of Cardiovascular Nursing* 2008; 7:3-9.
5. Lamura G, Mních E, Nolan M, Wojszel B, Krevers B, Mestheneos L, Döhner H. Family carers' experiences using support services in Europe: empirical evidence from the EUROFAMCARE study. EUROFAMCARE Group. *Gerontologist* 2008;48:752-771.8.
6. Ågren S, Hollman-Frisman G, Berg S, Svedjeholm R, Strömberg A. Addressing spouses unique needs after cardiac surgery when recovery is complicated by heart failure. *Heart Lung* 2009;38:284-91.
7. Ågren S, Evangelista L, Strömberg A. Do partners of patients with heart failure experience caregiver burden? *European Journal of Cardiovascular Nursing* in press 2010.
8. Beach SR, Schulz R, Williamson GM, Miller LS, Weiner MF, Lance CE. Risk factors for potentially harmful informal caregiver behavior. *Journal of American Geriatrics Society* 2005;53:255-261.

9. Molloy GJ, Johnston DW, Witham MD. Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure* 2005;7:592-603.
10. Moser DK, Dracup K. Impact of cardiopulmonary resuscitation training on perceived control in spouses of recovering cardiac patients. *Research in Nursing & Health* 2000;23:270–278.
11. Mårtensson J, Dracup K, Fridlund B. Decisive situations influencing spouses' support of patients with heart failure. A critical incident technique analysis. *Heart Lung* 2001;30: 341-350.
12. Daugherty J, Saarmann L, Riegel B, Sornborger K, Moser D. Can we talk? Developing a social support nursing intervention for couples. *Clinical Nurse Specialist* 2002;16:211-218.
13. Dracup K, Westlake C, Erickson V S, Moser D, Caldwell M L, Hamilton M A. Perceived control reduces emotional stress in patients with heart failure. *The Journal of Heart and Lung Transplantation* 2003;22:90-93.
14. Saunders MM. Family caregivers need support with heart failure patients. *Holistic Nursing Practice* 2003;17:136-142.
15. Gysels MH, Higginson IJ. Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. *Palliative Supportive Care* 2009;7: 153-162.
16. De Geest S & Sabaté E. Adherence to long-term therapies. Evidence for Action. *European Journal of Cardiovascular Nursing* 2003;2: 323.
17. Boyd KJ, Murray SA, Kendall M, Worth A, Frederick BT, Clausen H. Living with advanced heart failure: A prospective, community based study of patients and their carers. *European Journal of Heart Failure* 2004;6:585-591.
18. Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *ANS Advances in Nursing Science* 2000;23:82-97.

19. Duhamel F, Dupuis F, Reidy M, Nadon N. A qualitative evaluation of a family nursing intervention. *Clinical Nurse Specialist* 2007; 21: 43-49.
20. Stewart S, Vandenbroek AJ, Pearson S, Horowitz JD. Prolonged beneficial effects of a home-based intervention on unplanned readmissions and mortality among patients with congestive heart failure. *Archives of Internal Medicine* 1999;159:257-261.
21. Naylor MD, Brooten D, Campbell R, Jacobsen BS, Mezey MD, Pauly MV et al. Comprehensive discharge planning and home follow-up of hospitalized elders. *JAMA* 1999;281:613-620.
22. McAlister FA, Lawson FM, Teo KK, Armstrong P. A systematic review of randomized trials of disease management programs in heart failure. *American Journal of Medicine* 2001;110:378-384.
23. Blue L, Strong E, McMurray J, Davie A, McDonagh TA, Murdoch DR et al. Randomised controlled trial of specialist nurse intervention in heart failure. *British Medical Journal* 2001;323:715-718.
24. Strömberg A, Mårtensson J, Fridlund B, Levin LA, Karlsson JE, Dahlström U. Nurse-led heart failure clinics improve survival and self-care behaviour in patients with heart failure: results from a prospective, randomised trial. *European Heart Journal* 2003;24:1014-1023.
25. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review* 1977; 84:191-215.
26. Stuijbergen A, Becker H, Rogers S, Timmerman G, Kullberg V. Promoting wellness for women with multiple sclerosis. *Journal of Neuroscience Nursing* 1999; 31: 73–79.
27. Strömberg A, Dahlström U, Fridlund B. Computer-based education for patients with chronic heart failure. A randomised, controlled, multicentre trial of the effects on knowledge, compliance and quality of life. *Patient Education and Counseling* 2006;64:128-135.

28. Gayle BM & Preiss RW. An overview of dyadic processes in interpersonal communication. In *Interpersonal Communication Research: Advances Through Meta-Analysis*. New York., Lawrence Erlbaum Associates, Mahwah 2002; Chapter 7, 111-124.
29. Cook WL & Kenny DA. Examination the validity of self-report assessments of family functioning: a question of the level of analysis. *Journal of Family Psychology* 2006;20:209-216.
30. Ware JE. Conceptualization and measurement of health-related quality of life: comments on an evolving field. *SF-36 health survey manual and interpretation guide*. The New Health Institute, New England Medical Center, Boston. 1993.
31. Beck AT, Ward CH, Mendelson M, Mock J & Erbaugh J. An inventory for measuring depression. *Archives of General Psychiatry* 1961;4:561-571.
32. Beck AT, Steer RA, Brown GK. *Manual for the Beck depression Inventory-II (svensk version)*. Sandviken: Psykologiförlaget. 2005.
33. Moser DK, Dracup K. Psychosocial recovery from a cardiac event: the influence of perceived control. *Heart Lung* 1995;24:273-280.
34. Franzén Årestedt K, Ågren S, Flemme I, Moser D, Strömberg A. Psychometric properties of the Swedish version of the Control Attitude Scale for patients with heart disease and their family members. *European Journal of Cardiovascular Nursing* 2010;9(Suppl. 1):125.
35. Jaarsma T, Halfens R, Huijter AH, Dracup K, Gorgels T, van Ree J. Effects of education and support on self-care and resource utilization in patients with heart failure. *European Heart Journal* 1999;20:673-682.

36. Jaarsma T, Strömberg A, Mårtensson J, Dracup K. Development and testing of the European Heart Failure Self-Care Behaviour Scale. *European Journal of Heart Failure* 2003;5:363-370.
37. Elmståhl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of Physical Medicine Rehabilitation* 1996;77:177-182.
38. Andrén S, Elmståhl S. Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Science* 2005;19:157-168.
39. Moser DK, Dracup K. Role of spousal anxiety and depression in patients' psychosocial recovery after a cardiac event. *Psychosomatic Medicine* 2004;66:527-532.
40. Dunbar SB, Clark PC, Deaton C, Smith AL, De AK, O'Brien MC. Family education and support interventions in heart failure: a pilot study. *Nursing Research* 2005;54:158-166.
41. Dinesen B, Nøhr C, Andersen SK, Sejersen H, Toft E. Under surveillance, yet looked after: telehomecare as viewed by patients and their spouse/partners. *European Journal of Cardiovascular Nursing* 2008;7:239-246.
42. Fast YJ, Steinke EE, Wright DW. Effects of attending phase II cardiac rehabilitation on patient versus spouse (proxy) quality-of-life perceptions. *Journal of Cardiopulmonary Rehabilitation and Prevention* 2009;29:115-120.
43. Chung ML, Moser DK, Lennie TA, Rayens MK. The effects of depressive symptoms and anxiety on HRQOL in patients with heart failure and their spouses: testing dyadic dynamics using Actor-Partner Interdependence Model. *Journal of Psychosomatic Research* 2009;67:29-35.

44. Rohrbaugh MJ, Shoham V, Cleary AA, Berman JS, Ewy GA. Health consequences of partner distress in couples coping with heart failure. *Heart Lung* 2009;38:298-305.
45. Bekelman DB, Hutt E, Masoudi FA, Kutner JS, Rumsfeld JS. Defining the role of palliative care in older adults with heart failure. *International Journal of Cardiology* 2008;125:183-190.
46. Roccaforte R, Demers C, Baldassarre F, Koon T, Yusuf S. Effectiveness of comprehensive disease management programmes in improving clinical outcomes in heart failure patients. A meta-analysis. *European Journal of Heart Failure*. 2005;7:1133-1144.
47. Andrén S, Elmståhl S. The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing* 2008;17:790-799.
48. Chow SK, Wong FK, Poon CY. Coping and caring: support for family caregivers of stroke survivors. *Journal of Clinical Nursing* 2007;16:133-143.