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Caring needs in patient-partner dyads affected by heart failure

An evaluation of the long-term effects of a dyadic
psycho-educational intervention

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*To my family Per,
Alexander and Adam!*

Do not go where the path may lead,
go instead where there is no path and leave a trail.

Ralph Waldo Emerson

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ABSTRACT

Introduction: As medical treatment has improved, patients with heart failure (HF) now live longer and care mostly takes place at home with partners providing the main assistance. Taking care of an ill or disabled individual imposes a well-documented burden on the partner's health-related quality of life. The awareness of partners' burdensome situation is increasing, but few interventions have targeted the needs of patient-partner dyads with HF. The results have been inconclusive and give no clear guidance on how interventional programmes should be designed to improve both patient and partner outcomes.

Aim: The overall aim of this thesis was to evaluate the effects of a psycho-educational intervention delivered to patient-partner dyads with HF during long-term follow-up, and to explore the dyads' perceived caring needs.

Methods: The thesis is based on four papers that used both quantitative and qualitative data. Study I and II used a randomized controlled design with a follow-up assessment after 24 months including 155 patient-partner dyads. The control group received care as usual. The intervention group received care as usual, and in addition they participated in the nurse-led psycho-educational intervention. Data was collected using questionnaires before and 24 months after the intervention, in order to determine the long-term effects on patients and partners regarding health related quality of life, perceived control, symptoms of depression and partners' caregiver burden (I, II). A conceptual health promotion model inspired the intervention. To describe how the model was applied, a qualitative approach analysing nurses' documentation of the sessions with

71 dyads in the intervention group (III) was used. Study IV has an explorative design. To further explore the dyads' perceived caring needs, focus groups interviews with 19 patient-partner dyads with heart failure (IV) were performed.

Results: The intervention did not have any significant effect on physical or mental health- related quality of life, depressive symptoms, or perceived control over the heart failure among the dyads (I) or caregiver burden in the partners (II) after 24 months. Furthermore, time to first event did not differ significantly between the dyads in the intervention group and the control group (I, II). As for the partners, both the intervention and control group reported decreased physical health between the baseline assessment and the 24-month follow-up (I).

The intervention was composed of three components; 1) cognitive 2) supportive, and 3) behavioural component. The analysis of the nurses' documentation confirmed the coverage of all the components and the analysis revealed a wide range of caring needs among the dyads (III). The dyads described a need to learn about HF to be able to manage everyday life. Regular outpatient clinic visits and access to telephone support were vital and both the patient and the partner need to be present at the clinic visits. Meeting others who are in the same situation and sharing the burden in nurse-led group sessions was proposed as an opportunity to support each other and others (IV).

Conclusions: Over the 24-month follow-up period, the intervention had a neutral effect on health- related quality of life, depressive symptoms and perceived control over the HF among the dyads, and on partners' caregiver burden. Considering the fact that partners serve as a critical extension of the formal healthcare system, and that both patients and partners ask for more support, it will become crucial to find new ways to support dyads affected by heart failure. This thesis may be viewed as a

first step in trying to understand dyads' perceived caring needs, and it can serve as a guide in clinical work and when designing new dyadic interventions.

Keywords: Heart failure; intervention; caregiver burden; partner; dyad; nursing; qualitative content analysis; caring needs

LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

- I. Liljeroos M, Ågren S, Jaarsma T, Årestedt K, Strömberg A. Long Term Follow-Up after a Randomized Integrated Educational and Psychosocial Intervention in Patient-Partner Dyads Affected by Heart Failure. *PLoS One* 2015, 10: e0138058.
- II. Liljeroos M, Ågren S, Jaarsma T, Årestedt K, Strömberg A. Long-term effects of a dyadic psycho-educational intervention on caregiver burden and morbidity in partners of patients with heart failure: A randomized controlled trial. *Quality of Life Research* 2016, DOI 10.1007/s11136-016-1400-9 (E-pub ahead of print).
- III. Liljeroos M, Ågren S, Jaarsma T, Strömberg A. Dialogues between nurses, patients with heart failure and their partners during a dyadic psychoeducational intervention – a qualitative study. Submitted
- IV. Liljeroos M, Ågren S, Jaarsma T, Strömberg A. Perceived caring needs in patient-partner dyads affected by heart failure: a qualitative study. *J Clin Nurs* 2014, 23: 2928-2938.

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ABBREVIATIONS

ACEI	Angiotensin converting enzyme inhibitors
ARB	Angiotensin receptor blocker
BDI-II	Beck Depression Inventory-II
CAS	Control Attitude Scale
CBS	Caregiver Burden Scale
CRT	Cardiac Resynchronisation Therapy
HF	Heart Failure
HFmrEF	Heart Failure with mid-range Ejection Fraction
HFpEF	Heart Failure with preserved Ejection Fraction
HFrfEF	Heart Failure with reduced Ejection Fraction
HRQoL	Health-Related Quality of Life
ICD	Implantable Cardioverter Defibrillator
LVEF	Left Ventricular Ejection Fraction
MRA	Mineralcorticoid receptor antagonist
NYHA-class	New York Heart Association functional classification
QOL	Quality Of Life
RCT	Randomized Controlled Trial
SF-36	36-Item Short-Form Health Survey

INTRODUCTION

Heart failure (HF) is a common health problem worldwide, with a prevalence of 1-2% in the population and rising to $\geq 10\%$ among persons 70 years of age or older [1]. Patients with HF suffer from an irreversible and progressive condition, where periods of deterioration often lead to hospital admissions [1]. The symptom burden is often extensive and physical symptoms result in limitations in daily life and decreased health-related quality of life (HRQoL) [1]. Symptoms of depression and anxiety are common and are also potential prognostic predictors of hospitalisation in patients with HF [2, 3].

As treatment has improved, patients with HF now live longer, and the care mostly takes place at home with partners and family members providing the main assistance. Within the family, it is often the partner who takes on the caring role, and partners provide assistance and support for longer time periods compared to other family members [4, 5]. Partners form an important resource in supporting patients' self-care, such as medication adherence, symptom monitoring, and adherence to diet and exercise recommendations [6-8]. Partners are often the first to notice new symptoms, and patients and partners handle several health problems without consulting healthcare professionals [9].

At the same time, it should be acknowledged that HF could also affect partners negatively [10]. Taking care of an ill or disabled individual imposes a well-documented burden on the partner, both in terms of mental and physical health and the partner's HRQoL [11-13]. There is a relationship between the amount of caregiving and self-rated health; when the burden increases, so does the risk of illness among caregivers [14].

Despite the fact that HF has a number of negative consequences for both patients and partners, the majority of previous research has mainly focused on improving patients' outcomes. Self-care interventions for patients with HF aiming at improving patients' knowledge and skills in order to manage their condition are widely implemented in the care. These interventions reduce the risk of HF-related hospitalisations and all-cause death in most patients, but the same result has not been found for patients with depressive symptoms, which is common in the HF patient population [15, 16].

During the last few years, awareness of partners' burdensome situation has increased. A few intervention studies have targeted the needs of patient-partner dyads with HF, but mostly only short-term results between 4- 12 weeks have been reported. Furthermore, the results have been inconclusive and do not give clear guidance on how interventional programs should be designed to improve both patient and partner outcomes [13, 17-19]. Therefore, this thesis focuses on a long-term follow-up of a dyadic psycho-educational intervention, as well as on an exploration of the dyads' perceived caring needs in order to gain a better understanding of how to improve care for dyads affected by HF.

BACKGROUND

Heart failure

Definition, epidemiology and prognosis

Heart failure is a serious condition that is clinically defined as a syndrome resulting from an abnormality of cardiac structure or function. The abnormality results in a failure to pump enough blood, and thereby failure to deliver sufficient levels of oxygen to the body's metabolising tissues [1].

Heart failure is categorised as either HF with reduced left ventricular ejection fraction (LVEF) (HFrEF), also known as systolic HF, or HF with preserved LVEF (HFpEF), also known as diastolic HF. Systolic HF is due to impaired left ventricular contraction, which results in a reduced LVEF <40%. Diastolic HF is due to stiffness of the ventricle wall delaying filling of the heart chamber [1, 20]. Patients with LVEF between 40–49% are defined as mid-range HF (HFmrEF) [1].

Approximately 26 million people live with HF worldwide. In the United States alone, the prevalence is 5.7 million, and among countries represented by the European Society of Cardiology (ESC), an additional 15 million persons suffer from HF [21]. In Sweden, the estimated prevalence is 2.2%. In 2010, the mean age was 77 ± 13 years and 90% were 60 years old or above. Women are older than men at HF onset (mean age 76 vs. 70 years) because coronary artery disease occurs later in females [22]. Patients with HF consume large amounts of healthcare. In Europe and North America 1-3% of hospitalisations are due to HF, in total 1 million admissions have HF as the primary diagnosis [21, 23].

The most common cause for HF is coronary artery disease, such as angina pectoris or myocardial infarction, although hypertension and diabetes are

contributing factors in many cases. Other causes are, for example, cardiomyopathy, arrhythmia, and valvular heart diseases [1].

Mortality from HF has declined during the last few decades but the prognosis is still poor. The estimated five-year mortality is between 48-65% after the initial diagnosis [24]. In Sweden, the estimated one-year mortality is 24% in patients with New York Heart Association functional classification (NYHA) class III and 50% in patients with NYHA class IV, Figure 1 [25, 26]. The HF prognosis is related to symptom severity, where deterioration in symptoms indicates an increased risk for hospitalisations and death. The LVEF is also considered an important prognostic factor; the lower the LVEF, the poorer the survival rate [1].

Symptoms, signs and multi-morbidity

Patients with HF often experience multiple symptoms simultaneously, and many symptoms are associated with adverse outcomes. Typical HF symptoms are breathlessness, fatigue, reduced exercise tolerance and ankle swelling, fluid retention, impaired cognitive function, and loss of appetite. Specific HF signs are elevated jugular venous pressure, third heart sound, and cardiac murmur [1, 27]. Fatigue is highly prevalent in patients with HF and has been associated with depressive symptoms, decreased exercise capacity, and dyspnoea [27, 28]. Heart failure leads to different levels of symptom severity, described by the NYHA-class, Figure 1. The classification has four stages (I-IV), based on how limited patients are during physical activity. An increase in NYHA-class means an increase in symptom severity [26].

Multi-morbidity in HF, defined as HF of any aetiology and multiple concurrent conditions that require active management, constitutes a growing problem within the ageing HF-population worldwide. Multi-morbidity differs from co-morbidity, which refers to a condition existing simultaneously but independently of another condition, unlike multi-morbidity where conditions are linked and concurrent with each other

[29-31]. Heart failure in isolation is rare in the HF- patient population aged 75 years and older. In Europe, a quarter of the population suffer from multi-morbidity, and 33% of patients aged 75 years or older have two to four concurrent conditions that often require different forms of self-care management [32]. The risk of hospitalisation, re-hospitalisation and death increases with the number of chronic conditions [33]. Some of the most common concurrent conditions behind high levels of morbidity and mortality are diabetes and metabolic disorders, renal impairment, arrhythmias, and respiratory disorders [29]. Guidelines describe that multi-morbidity is a distinct clinical entity, and a goal-orientated approach must be applied to improve health outcomes [1, 34].

NYHA I

No limitation, ordinary physical exercise does not cause undue fatigue, dyspnoea or palpitation.

NYHA II

Slight limitation of physical activity, comfortable at rest but ordinary activities result in fatigue, dyspnoea or palpitations.

NYHA III

Marked limitation of physical activity, comfortable at rest but less than ordinary activities result in fatigue, dyspnoea or palpitations.

NYHA IV

Unable to carry out any physical activity without discomfort, symptoms of HF are present even at rest with increased discomfort with any physical activity.

Figure 1. New York Heart Association functional classification [26].

Pharmacological and device treatment

The goals of HF treatment are to relieve symptoms, prevent hospital admission, and improve survival [1]. Basic pharmacological treatment, which should be considered in every patient, is angiotensin converting enzyme inhibitors (ACEI) or angiotensin receptor blocker (ARB) as an alternative in patients intolerant of ACEI, a beta-blocker, and a

mineralcorticoid receptor antagonist (MRA). The medications are often used together with a diuretic that is given to relieve symptoms and signs of congestion [1]. As the number of co-morbid diseases in older patients with HF has increased, polypharmacy is common. The average older adult with HF takes more than six chronic prescription medications, which can make the medical treatment difficult to manage [35].

As a complement to medical treatment, device treatment consisting of cardiac resynchronisation therapy pacemakers (CRT) and implantable cardioverter defibrillators (ICD) can be implanted. These devices can improve heart function, exercise capacity, correct potentially lethal ventricular arrhythmias, and relieve symptoms in selected patients [1, 36].

Self-care in heart failure

Effective HF self-care is important for maintaining health and to prevent patients from HF exacerbation [15, 37]. Self-care has been described as a naturalistic decision making process that consists of three components; self-care maintenance, self-care monitoring, and self-care management [38]. Self-care maintenance refers to daily HF-related health activities, and self-care management refers to behaviours required from the patient when HF symptoms occur [38]. Self-care maintenance includes behaviours to maintain physical and emotional stability and is linked to self-care monitoring where the goal is to recognise changes in signs and symptoms. Self-care management includes evaluation of symptoms and response to these before deterioration, and also evaluation of the effectiveness of actions taken [38]. HF- specific self-care behaviours include taking prescribed medications, keeping physically active, eating healthy, avoiding excessive salt intake (>6 g/day), avoiding excessive fluid and alcohol intake, maintaining a healthy body weight, stop smoking and taking recreational substances, and receiving immunisation against influenza and pneumococcal disease. Self-care management also includes

daily monitoring and recognition of changes in signs and symptoms, knowing how and when to contact healthcare professionals and, in line with professional advice, know when to self-manage diuretic therapy [1, 37, 38].

Self-care is often impaired by the burden of multi-morbidity and sequelae of HF, such as depression, impaired cognition, and limited awareness of declining health [39-41]. Patients with HF need knowledge in order to be able to implement self-care strategies, but there are discrepancies between obtaining and remembering information [42]. Although patients' knowledge increases after educational interventions, outcomes are not always improved, which elucidates the complexity of HF self-care [43]. It is known that structured nurse-led HF management programs are beneficial in terms of reducing morbidity and mortality and increasing patients' quality of life (QOL) [44, 45]. According to both international and Swedish national HF guidelines [1, 46, 47], there is a strong recommendation that patients with HF receive care at a nurse-led HF clinic, where the nurses optimise the medical treatment and patients receive HF-specific education on how to perform self-care activities and handle medication. Today, there are HF clinics with specialist-trained nurses in almost all Swedish hospitals.

Dyads affected by heart failure

The majority of patients affected by HF live with a family member who is involved in the care as an informal caregiver. Throughout this thesis, it is the partner that is the informal caregiver and the terms partner, spouse and informal caregiver is used interchangeably. The known needs of patient-partner dyads with HF are multifaceted, and in this thesis the dyads' health-related quality of life (HRQoL), perceived control, depressive symptoms and partners' caregiver burden are focused upon.

Patient-partner dyads living with heart failure

Between 45-70% of patients with HF live with a family member who is involved in the care as an informal caregiver. Where the patient and the partner are living in a dyadic relation, the partner is usually the primary caregiver [48]. Supportive relationships where self-care activities could be shared with a partner are known to improve outcomes, such as self-care, adherence, and HRQoL in patients with HF [7, 8, 49].

The concept 'dyad' can be defined as two individuals maintaining a sociologically significant relationship [50]. The adjective, 'dyadic' describes the interaction between the individuals. The strength of a dyadic relationship is built on the basis of time the individuals spend together, as well as on the emotional intensity of their relationship [51]. A caring and warm relation provides calm and steadiness and can positively influence health outcomes, while a distressed relation can have a negative impact on physiological outcomes [52]. Patient-partner dyads generally have many characteristics in common, for example, similar age, level of education, and socio-economic status [53]. Often, they also have comparable health behaviours [54], and influence each other's self-care behaviour and QOL [53]. Patients' self-care maintenance, management and confidence have been found to correlate with the partners', and emotions are contagious between patient-partner dyads [53]. Patients' mental health and partners' perceived burden have also been shown to impair the dyad's relation, causing difficulties in communication and emotional distress in both patients and partners [55, 56]. It is therefore important to understand and support the dyad as a care unit.

Three typologies of HF patient-partner dyads that act differently in the supporting and caring situation have been described [57]. There is *the novice dyad*, where patient and partner contribute to different aspects of HF self-care without cooperation, often resulting in poor self-care management. The second group is *the inconsistent dyad*, where partners contribute and support with self-care activities in the areas where self-

care is the most insufficient in the patient. The last group is *the expert dyad* group. Here, dyads collaborate in all aspects of HF self-care, have the best relationship quality, and partners have the lowest caregiver strain. Identifying dyad typology before a supportive intervention might result in better dyadic outcomes [57].

Guidelines emphasise the importance of the patients' own responsibility regarding HF self-care [1]. To be able to shoulder this responsibility, patients need education and support from healthcare professionals. Partners are often motivated to support the patient; however, dyads ask for support from healthcare professionals to be able to manage HF in everyday life [58, 59]. During the illness trajectory, different types of support may be needed. During the period immediately after diagnosis, support might be focused on helping the dyad to cope in the new situation and assist them in managing a complex medication routine. After that, the need for psychosocial support might be more relevant to motivate the patient to adhere to lifestyle changes supported by a partner. Later on, emotional support to deal with the loss of independence and social isolation might be needed [60].

Dyads' perceived health-related quality of life

Health-related quality of life is a multi-dimensional concept that includes different aspects related to physical, mental, emotional, and social functioning. The concept focuses on the impact health status has on quality of life. A related concept to HRQoL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction [61].

Poor HRQoL in patients with HF has been found to be an independent predictor of higher hospitalisation and mortality rates [62, 63]. Patients with HF also have significantly lower HRQoL and more depressive symptoms compared with age- and sex-matched controls [64]. Relatively high levels of deteriorating mental HRQoL have also been identified

among partners, sometimes even higher than in the HF patients [65, 66]. One third of partners perceive a moderate caregiver burden and are therefore at higher risk of poor HRQoL [58]. Measuring HRQoL can identify person-centred problems and improve the understanding of a person's subjective experience of health. This is important when evaluating outcomes and may promote communication between patients, partners and healthcare providers [67, 68].

Dyads' perceived control over the heart failure

Perceived control can be defined as a self-generated belief that a person has the internal resources to influence adverse events positively and bring about a desired change in his/her environment [69]. To be diagnosed with HF is a stressful event that can trigger a variety of coping efforts. Some patients develop feelings of control related to their condition as a coping response. Patients with HF with low perceived control are less likely to engage in self-care strategies and are less likely to seek help early. They have poorer outcomes than those with normal perceived control [70, 71]. Several studies have shown that partners experience lower perceived control than the HF patients themselves [72, 73]. Perceived control is independently associated with HRQoL. If a person can regain control, then they are more likely to manage self-care, which can improve HRQoL and well-being [71].

Partners' perceived caregiver burden

Caregiver burden can be defined as a multi-dimensional response to the demands, perceived strain and burden that result from supporting someone ill [11, 74]. Patients with moderate to severe HF are often reliant on their partners for assistance with daily activities, i.e., shopping, cooking and housekeeping, and sometimes also with personal care, such as bathing and dressing [75]. Caregiving demands have been associated with both mental burden, for example, symptoms of depression and anxiety, and physical health risks [76, 77]. There is a relationship between

the amount of care provision and self-estimated health, and when the burden increases, so does the risk of illness among caregivers [14]. Caregiver burden increases if the partner experiences poor mental and/or physical health and has limited social and professional support [56].

The burden can be a direct result of caregiving responsibilities, such as physical burden caused by lifting and dressing a disabled partner, fatigue from the hours of caregiving [78], or an indirect psychological/emotional result of knowing that a family member is ill [79]. Less commonly noted, caregiving can be perceived as beneficial, mainly through feelings of altruism and fulfilment of familial obligations [80].

Interventions targeting dyads with heart failure

Guidelines [1] recommend that multidisciplinary HF management programs should be used to improve outcomes. The programs should include patient education, optimisation of medical treatment, and psychosocial support [1]. Teaching strategies should be individualised and reflect the patient's knowledge, ability to learn, cognitive function and motivation [42]. Awareness of the links between the patient's illness and the relationship with the partner is increasing and has led researchers to modify patient-focused psychosocial interventions in chronic diseases to also include the patient's family, most commonly the partner [17, 81]. However, patient-partner dyads have only been included in a few randomised controlled trials (RCT) in the HF- population. Most of the studies have only evaluated results up to 8 months, and have used different designs, methods and outcomes, Table 1.

A three-arm RCT study tested if a family- patient education intervention reduced the patient's dietary sodium intake. Both shared education and

family partnership communication reduced intake over four to eight months, compared to usual care. However, the patients' medication adherence, knowledge about HF and perceived autonomy support did not improve and family criticism did not decrease [82, 83].

A problem-based coping intervention addressed the specific needs of families caring for hospice patients with HF, and the primary target was the partner. However, no statistically significant improvement in caregiver QOL could be seen in the partners [84].

A three-session educational intervention aimed to define the effect of a family support program on HF self-care behaviours and found a significant difference in self-care, where the intervention group reported greater frequency of self-care behaviours than the control group [85]. A theoretically based non-randomised Shared Care intervention was tested in family care, aiming to increase support between the dyads. At the end of the intervention, the patients had improved self-care. For the caregivers, there were improvements in relationship quality and health [86].

Different types of eHealth designs have also been tested in dyads with HF. One study aimed to determine whether automated feedback to partners of HF patients had an impact on caregiving burden and assisted with self-care management. The result showed that when partners experienced significant caregiving strain and depression, weekly systematic email feedback, including summaries and suggestions for self-care assistance, decreased those symptoms and increased engagement in the patient's self-care [87]. A pilot study using telemonitoring by an advanced practice nurse after discharge from a hospitalisation due to HF found no effect on emergency department visits, costs, or risk of readmission for patients with HF [88].

Table 1. Overview of intervention studies including dyads with HF.

Study	Dyads (n)	Age	Type of Intervention and design	Length of intervention/ follow -up
Dunbar et al. (2013) [82, 83]	117	Dyad 55.9±10.5	RCT; Family education on dietary and medication adherence	2 weeks/ 4 and 8 months
McMillan et al. (2013) [84]	60	Dyad 63.3 ±13.4	RCT; Problem-based coping intervention	5 weeks/ 5 weeks
Piette et al. (2015) [87]	369	Dyad 47.1±13.2	RCT; Systematic email feedback	12 months/ 6 and 12 months
Schwarz et al. (2008) [88]	102	Dyad 63.5±16.1	RCT; Telemonitoring	90 days/ 90 days
Shahriari et al. 2013 [85]	64	NA	RCT; Family support program	3 weeks/ 1 month
Sebern et al. (2012) [86]	7 patients 10 partners	Patient 80±9.5 Partner 61±19	Non randomised; Shared Care Dyadic intervention	12 weeks/ 12 weeks

There have also been interventions targeting only partners of HF patients [89-93]. Two studies used telehealthcare and phone support, which resulted in reduced caregiver burden and higher stress mastery [89, 90]. Another study tested an exercise intervention to patients where partners also could choose to participate. After 6 months, there was a significant difference in caregiver burden, where partners in the exercise group reported significantly higher caregiver burden [93].

Different forms of educational sessions have been tested. A supportive educative partner group intervention consisted of four weekly multimedia-training sessions. The result showed a significant reduction in the caregivers' burden in the intervention group and an increase in the control group [91]. A group-based multi-professional educational program for family members of patients with HF did not find any significant differences in anxiety, depression, or quality of life between the intervention group and control group [92].

The psycho-educational dyadic intervention evaluated in this thesis

The lack of conclusive research on how to best support HF dyads served as an inspiration to develop and test a psycho-educational intervention that combined education and psychosocial support in dyads of patients with HF and their partners. The intervention was delivered during three nurse-led sessions at the HF outpatient clinics at one university hospital and one county hospital or in the dyads home, between 2005 to 2008. The sessions were scheduled 2, 6 and 12 weeks after discharge from hospital and each session lasted approximately 60 minutes. The intervention was delivered through nurse-led face-to-face counselling, a computer-based CD-ROM HF educational program [94], and written HF teaching materials. The nurses brought a computer to the dyads' home when needed, to make sure all dyads had access to the CD-ROM program.

The dyads in the control group received care as usual, both in the hospital and the follow-up with medical appointments and at the nurse-led HF outpatient clinic at the hospital. Care as usual included optimised medical treatment according to guidelines [95], and verbal and written patient education about the disease and self-care management. Standard care focused on the patient's needs, and although partners were able to join, they were not systematically invited to participate during the follow-up appointments.

The dyads in the intervention group received care as usual, and in addition they participated in the nurse-led psycho-educational intervention, Table 2. The intervention included education and psychosocial support to maintain and strengthen the dyads' physical and mental function and perceived control over the disease. Each session included HF education and help to develop problem-solving skills to assist the dyads in recognising and modifying factors that contribute to psychological and emotional distress.

During the first session the focus was to increase the dyads' knowledge of the disease and treatment, strengthen the dyads' mental and physical functions, and introducing self-care behaviours, such as daily weight monitoring, adherence to medical treatment, and a flexible diuretic intake. The second session aimed at increasing knowledge of lifestyle changes, assessing and discussing the patient's need for support, modifying and strengthening caregiver behaviour, and identifying barriers for lifestyle changes. The third session focused on increasing knowledge of HF self-care and outcomes and implementing strategies for self-care management and maintenance. The dyads received a reinforcement of the intervention including an assessment of outcomes on support and behaviour. The session also assessed the partner's need for support and perceived caregiver burden in order to find strategies to improve the partner's control. Plans for the future were made.

Four HF nurses, two from each hospital, delivered the intervention. All four nurses were experienced in caring for patients with HF and worked at the nurse-led HF clinic or at a hospital ward treating HF patients. Prior to the intervention they had attended three days of theoretical and practical training on how to deliver the intervention, given by the research team. On several occasions during the time for the intervention, the study team visited the HF clinics and assessed the nurses' competence and study fidelity through observations and consultations to ensure that the model was implemented throughout the study and the documentation was performed as instructed.

Table 2. Content of the three modules in the intervention.

	Session 1	Session 2	Session 3
Cognitive Component	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
Cognitive Outcomes	Increased knowledge on the chronic HF syndrome and treatment	Increased knowledge on the rationale for lifestyle changes	Increased knowledge on HF care and outcomes
Support Component	Introduce psychosocial support concept	Assess patient's need of support and caregiver behaviour	Assess partner's need of support Discuss partner's burden
Support Outcomes	Improved mental and physical functions	Strengthened self-care behaviour	Improved mutual support Decreased caregiver burden Improved control
Behavioural Component	Intentions, abilities and self-efficacy regarding self-care	Barriers to lifestyle modifications	Strategies to improve or maintain self-care behaviour
Behavioural Outcomes	Daily weighing Monitoring of symptoms Flexible diuretic intake Adherence	Salt and fluid restriction Influenza and Pneumococcal immunisations Regular Exercise	Identifying life priorities and planning for the future
Teaching material	Written material CD - ROM	Written material CD - ROM	Written material CD-ROM
Tools for supportive counselling	Dialogue guide part 1	Dialogue guide part 2	Dialogue guide part 3

The conceptual health promotion model

The intervention was inspired by a health promotion model developed by Stuifbergen et al. [96], Figure 2. The model was originally developed for patients with multiple sclerosis, a chronic disease with a similar clinical path as HF, with burden of fatigue and decreased physical ability [96, 97]. The model previously only focused on patients, but as partners form an important resource in supporting patients' HF self-care, the model was used for the patient-partner intervention.

The concepts in the model are developed from Pender's model of health promotion [98] and Bandura's self-efficacy theory [99]. The assumption is that development of knowledge and skills reduces barriers and enhances resources and self-efficacy. This will result in better health promoting behaviours, such as self-care. Self-efficacy can be defined as a person's belief in his or her ability to succeed in a particular situation [100]. Persons with high self-efficacy have been found to be more likely to view perceived difficulties, such as self-care activities, as something to be

mastered rather than something to avoid [100]. Gaining knowledge about disease management is viewed as the basis for the choice of behaviours to sustain and enhance HRQoL [96, 101].

Previous interventions designed within this model had a cognitive component delivering information, but the major component focuses on improving the patient's self-efficacy by identifying barriers, enhancing resources, increasing support and helping to develop skills and beliefs in one's own capacity to achieve desired behaviour changes. Therefore, the model was modified to include barriers, resources and self-efficacy in all of the three components delivered in the intervention, i.e., cognitive, supportive and behaviour components (Figure 2). The three components and their content were based on a literature review on known aspects of dyads' psycho-educational needs.

The intervention focused on problem-solving, information acquisition, self-care management, and emotional and social support to the dyads. The nurses delivering the intervention assisted the dyads in recognising and modifying factors that contributed to physical and emotional distress by supporting them in changing their thoughts and rooted behaviours, and implementing strategies for self-care management and maintenance.

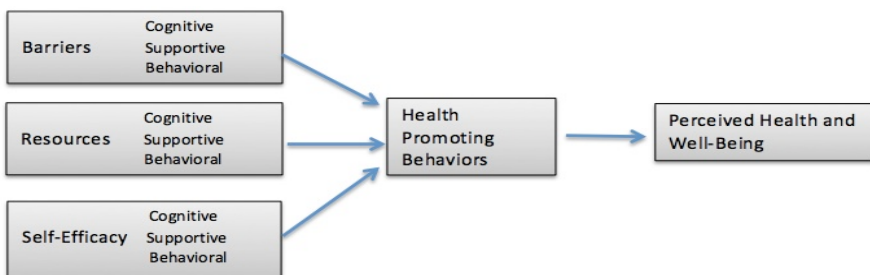


Figure 2. The conceptual health promotion model used as an inspiration to the intervention.

Rationale

Heart failure is a serious condition characterised by poor prognosis, frequent hospitalisations and high risk for early readmissions due to worsening HF symptoms. The medical treatment aims to reduce morbidity and mortality, and to improve symptoms and HRQoL. Counselling and education are also important parts of the treatment in order to improve the ability to perform self-care activities. Nevertheless, despite most patients receiving education, many are not able to adequately engage in self-care activities, which is a contributing factor to the high number of readmissions.

Having the support of a partner is important for patients with HF. Partners have the potential to improve self-care, such as increase adherence to treatment, and support patients with monitoring and management of symptoms. At the same time, it should be acknowledged that supporting the patient could also affect the partner negatively and cause caregiver burden. However, emotional reactions of burden and stress decrease when partners experience control over the HF.

Despite HF having a number of negative consequences for both patients and their partners, research addressing psycho-educational needs from a dyadic perspective is rare. Until recently, contemporary care has remained patient- focused, although the importance of partner support is increasingly emphasised. The results from the limited number of dyadic studies conducted so far have been inconclusive and have not presented effective interventions for improving outcomes for patients and partners with HF. Therefore, further studies focusing on the HF patient-partner dyad are needed. In addition, most previous research has only evaluated short-term effects of dyadic intervention programs, while long-term effects might be of equal importance.

This inspired our research group to develop and test a nurse-led dyadic intervention that combined psychosocial support and education in dyads

of patients with HF and their partners, where the dyad participated together as equals throughout the whole intervention. The 3-month results showed significant differences in the patients' perceived control over their HF, but the differences did not remain after 12 months and no significant effect was seen among the partners. As for the dyads' HRQoL and symptoms of depression, there was no difference between the groups after one year [102].

Patients with HF experience great variability in symptoms to which they must respond, and the need for self-care management behaviours vary considerably over time [1, 38]. As HF is a chronic condition, the involvement and burden for partners is likely to increase during the illness trajectory. A significant interaction has been found between involvement in care and performing caregiving tasks for several domains of HRQoL in partners of patients with HF [14, 65]. During the time of the intervention the patients were quite stable [102]. However, in times of instability or deterioration, both patients and partners might have benefited from the skills they had learned from the intervention.

This thesis includes the 24-month follow-up after a dyadic psycho-educational intervention and focus groups interviews. The thesis provides new knowledge about how dyads describe their perceived caring needs, which can help in the design of future dyadic interventions.

AIMS

The overall aim of this thesis was to evaluate the effects of a psycho-educational intervention delivered to patient-partner dyads with HF during long-term follow-up, and to explore the dyads' perceived caring needs.

The specific aims of the studies were:

- I. To determine the 24-month effects of an intervention with psycho-educational support in dyads of heart failure patients and their partners.
- II. To describe the 24-month effects from a psycho-educational intervention in relation to caregiver burden and morbidity in partners to heart failure patients.
- III. To describe nurses' documentation of the content in a psycho-educational intervention inspired by Stuijbergen's model addressing cognitive, supportive and behavioural needs of patient-partner dyads affected by HF.
- IV. To explore the perceived caring needs in patient-partner dyads affected by heart failure to develop an understanding of potential areas to support.

METHOD

Design

This thesis is based on four studies using both quantitative and qualitative methods for data collection and analysis. By combining different quantitative and qualitative methods, a richer and more in-depth description of dyads' caring needs could be described [103, 104].

All studies in this thesis were based on quantitative and qualitative data collected in a project where the main focus was a randomised controlled design in order to evaluate the effects of a psycho-educational intervention to patient-partner dyads affected by HF (ClinicalTrials.gov, identifier: NCT02398799).

Data was systematically collected using questionnaires before and 24 months after the intervention, in order to determine the long-term effects on patients and partners regarding physical and mental HRQoL, perceived control, symptoms of depression and partners' caregiver burden (I, II). To gain a better understanding of how well the conceptual health promotion model [96] that inspired the intervention suited and to what extent it was used, a qualitative approach was applied to analyse the nurses' documentation in dialogue guides used during the intervention (III). To further explore the dyads' perceived caring needs, focus groups interviews with patient-partner dyads from both the intervention group and the control group (IV) were performed. An overview of the designs and methods is shown in Table 3.

Table 3. Overview of design, methods, analyses and outcomes in study I-IV.

	Study I	Study II	Study III	Study IV
Approach	Quantitative	Quantitative	Qualitative	Qualitative
Design	Randomised, controlled	Randomised, controlled	Descriptive	Explorative
Participants	155 patient-partner dyads affected by HF	155 partners of patients affected by HF	71 patient-partner dyads (intervention group)	19 dyads (intervention and control group)
Data collection	Questionnaires; SF-36, BDI-II, CAS	Questionnaires; SF-36, BDI-II, CAS, CBS	Nurses' documentation in dialogue guides	Focus group interviews
Data analyses	Descriptive statistics, Kaplan Meyer survival analysis, Linear regression analyses	Descriptive statistics, Independent and dependent sample t-test, Cohen's d effect size, Logistic regression	Direct deductive qualitative content analysis	Inductive qualitative content analysis
Time data collected	Baseline and after 24 months	Baseline and after 24 months	During the intervention	12-24 months after the intervention
SF-36= 36-Item Short-Form Health Survey, BDI-II= Beck Depression Inventory II, CAS= Control Attitude Scale, CBS= Caregiver Burden Scale				

Setting and participants

The participants were recruited at one university hospital and one county hospital in the southeast region of Sweden between January 2005 and December 2008. The same cohort was used in all studies. A flowchart of the inclusion and data collection in study I -IV is presented in Figure 3.

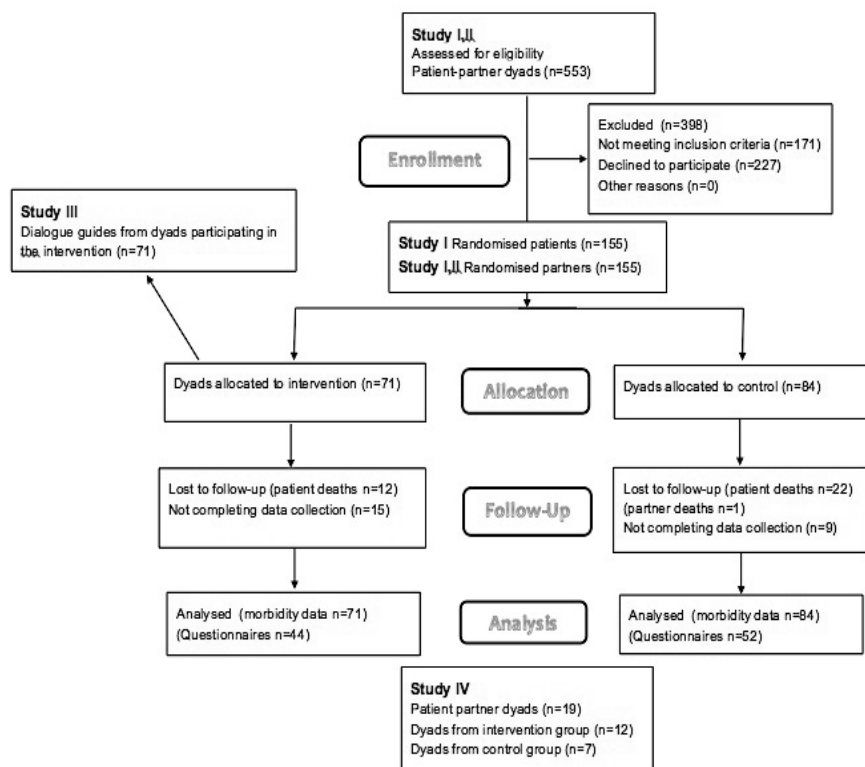


Figure 3. Flowchart for study I –IV.

All patients diagnosed with HF recently admitted to hospital due to deterioration of HF were screened weekly by members in the research team (I, II). The inclusion criteria were: being a dyad consisting of a patient diagnosed with HF according to the European Society of Cardiology guidelines [105], in NYHA class II-IV, recently discharged from hospital (i.e., in the last two to three weeks) following acute exacerbation of HF, and cohabiting with a partner in a marriage-like relationship. Exclusion criteria were: diagnosed dementia or other severe psychiatric illnesses, drug abuse, difficulties for one of the dyad members to understand or read the Swedish language, planned cardiac surgery, or participation in other studies.

During the intervention the nurses used a semi-structured, five-page dialogue guide for guidance regarding the content of each session. The nurses wrote down summaries of the discussion with all dyads in the intervention group in their dialogue guides during each intervention session. The data in study III consisted of the nurses' handwritten documentation.

A purposeful sampling from the RCT study (I) was selected for inclusion of dyads in the focus group study (IV). This sample was made to ensure variation in age, gender, and group assignment. The participants were recruited between March and June 2011, both from the control group (n = 8) and the intervention group (n = 11).

Sample size

A power analysis was conducted to justify the sample size in study I-II. Lack of evidence for clinically relevant improvements in the outcome variable scores made it difficult to estimate a relevant difference score between the intervention and control group. Therefore, a pre-defined medium effect size for regression models was used. With an expected medium effect size ($f^2 = 0.10$), a statistical power of $1 - \beta = 0.90$, and a 5% significant level, the estimated sample size was determined to 108 participants, 54 in each group. As the statistical models needed to be adjusted for the fact that patients and partners were nested within dyads, the sample size was doubled. Thus, a sample size of 216 individuals (108 dyads) was expected to be sufficient. As the dropout frequency was expected to be high during the 24-month follow-up period, an additional 47 dyads were recruited.

Procedures

A member of the research team verbally informed the dyads of the studies by a telephone call or during a visit at the HF outpatient clinic (I, II). If both the patient and the partner were interested in participating in the

RCT study they were given additional oral and written information. In order to be included in the study both the patient and their partner had to give consent. After written consent the dyads were randomised to either the control or interventional group, using a random number table with blocks of 12. Thereafter, questionnaire packets were sent out by mail (I, II). The dyads were instructed to fill in the questionnaires separately. If the patient or partner in a dyad died or could not complete the questionnaires at 24 months, the other person did not need to complete the questionnaires either. The dyads returned the questionnaires by mail in a pre-paid postage return envelope. After 2 weeks one reminding phone call was made to non-responders.

The intervention sessions were conducted in the dyads' homes or at the HF clinic, depending on the dyad's preference (I-II).

Prior to the intervention the nurses delivering the intervention had received information on how to perform the sessions, how to use the dialogue guides, and how to document the dialogues with the dyads. The nurses were informed that their documentation should be analysed (III).

Dyads were invited to the focus group interviews (IV) by a letter addressed to both the patient and the partner. The letter described the purpose of the study and the time and place for the interview. They replied by mail in pre-paid postage return envelope and reported if they wished to participate or not. Both patients and partners signed an informed consent. The focus group interviews took place in an undisturbed room outside the outpatient HF clinics (IV).

Data collection

In this thesis, different methods for data collection were used to determine the effect of the intervention and to capture different perspectives of the dyads' perceived caring needs.

Quantitative data collection (I, II)

Collection of quantitative data was made by self-administered questionnaires, including validated instruments to measure self-rated HRQoL (36-Item Short-Form Health Survey) [106, 107], symptoms of depression (Beck Depression Inventory II) [108, 109], perceived control (Control Attitude Scale) [110], and caregiver burden (Caregiver Burden Scale) [111], Table 4. In addition, background data was collected (I- II). Demographic and health history data regarded co-morbidity, employment, education, exercise, smoking, and alcohol habits were collected using a self-administered questionnaire. Morbidity data was collected from patients' and partners' medical records by the author who was blinded to group assignment. Both the patient and the partner filled in all instruments, except the Caregiver Burden Scale, which was only completed by the partners (II).

Table 4. Overview of the instruments (I, II).

	Number of items	Theor- etical range	Internal consistency reported by instrument developer*	Internal consistency in study I-II*	Study
Health- related quality of life					
36-Item Short- Form Health Survey	36	0-100	0.80 in all dimensions	>0.70 in all dimensions (range 0.71- 0.93) for both patients and partners	I,II
Symptoms of depression					
Beck Depression Inventory II	21	0-63	0.91	Patients 0.92 Partners 0.90	I,II
Individual's perceptions of control					
Control Attitude Scale	4	4-28	Patients >0.80 Partners 0.60-0.70	Patients 0.80 Partners 0.80	I,II
Caregiver burden					
Caregiver Burden Scale	22	22-88	0.70-0.87, except for environment, 0.53	Total score 0.93 Subscales 0.67-0.88	II

*Cronbach´s *a* coefficient

Instruments

The 36-Item Short-Form Health Survey

The 36-Item Short-Form Health Survey (SF-36) was used to assess physical and mental health. The instrument includes eight multi-item scales containing two to ten items each, and a single item to assess health transition. All items are scored from 2-6.

The eight health domains include physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), general health (GH), vitality (energy/fatigue) (VT), social functioning (SF), role limitations due to emotional problems (RE), and mental health (psychological distress and psychological wellbeing) (MH).

The health domains are weighed together in two composite scores; physical component score (PCS) and mental component score (MCS). For each of the eight dimensions, scores were coded, summed and transformed to a scale from 0 (worst possible health) to 100 (best possible health). The SF-36 has been frequently used and has been found to have good reliability and validity [106, 107].

The Beck Depression Inventory II

The Beck Depression Inventory II (BDI-II) is a 21-item instrument assessing different symptoms of depression [108]. Each answer is scored on a scale from 0 to 3, indicating feelings over the last two weeks. Higher scores indicate more severe depressive symptoms.

The constructors' recommended cut-off scores are: 0–13 (no depression), 14–19 (mild depression), 20–28 (moderate depression), and 29–63 (severe depression). A validated Swedish version of the instrument was used [109].

The Control Attitude Scale

The Control Attitude Scale (CAS) is an instrument consisting of four belief statements designed to measure perceptions of personal and family control in the context of cardiovascular disease. The instrument was developed to measure the degree to which individuals perceive situational control (and conversely helplessness) related to their heart disease. The CAS contains items that relate to both the individual's own perception of control and their perception of the degree to which a family member

perceives control over the heart disease. The items measuring family control are included based on the theoretical assumption that the patient's and family member's perceptions of situational control are mutually influential [110].

Response statements are scored on a scale from 1 (none) to 7 (very much). The total score range ranges from 4 to 28, with higher scores reflecting higher levels of perceived control. Reliability testing in different language versions has revealed satisfactory internal consistency [110, 112, 113].

The Caregiver Burden Scale

The Caregiver Burden Scale (CBS) (22- item) is used to assess the burden that family caregivers experience regarding the caring responsibility they have to take on when a family member suffers from a chronic disease [111]. The CBS consists of five indices: General strain (8 items) concerns the caregiver's lack of personal freedom. Isolation (3 items) reports on limited private time and limited social interaction. Disappointment (5 items) involves loneliness, physical and financial burden. Emotional involvement (3 items) contains items covering embarrassment and anger. Environment (3 items) concerns partners' perceptions of not managing to handle practical problems related to caregiving.

The scale score is the mean of all items, and responses are scored from 1-4 (not at all, seldom, sometimes, often). Higher scores indicate higher burden. The total index is divided into three groups; 1.00–1.99 indicates low burden, 2.00–2.99 indicates medium burden and 3.00–4.00 indicates high burden [111]. In general, the CBS has demonstrated satisfactory psychometric properties in previous studies [111, 114].

Quantitative data collection (III, IV)

Nurses documentation

A dialogue guide was constructed based on Stuifbergen's model [96] covering cognitive, supportive and behaviour needs in patient-partner dyads affected with HF. The guide gave structure for both the discussion and documentation for the nurses during the three psycho-educational sessions.

The data consisted of the nurses' handwritten documentation in the five-page dialogue guides (III). In the dialogue guide, the nurses summarised the discussions, agreements and difficulties described by the dyads during each of the three sessions. The dialogue guide served as a foundation in the discussions, but the dyads were encouraged to narrate and discuss all matters they found important. The data in the dialogue guides from 71 patients with HF and their co-habiting partners was analysed.

Focus group interviews

To be able to further explore and capture the patients' and partners' perceived caring needs, eight focus group interviews were performed (IV). Two to three dyads participated in each focus group and the interviews lasted 50-90 minutes.

The research team first developed an interview guide with seven questions related to the aim of the study, Table 5. The first interview was performed as a pilot to test the questions. As the interview guide worked well and no changes were made, the pilot interview was included in the analysis.

A moderator was in charge of the interviews. There was also an observer attending, who was responsible for taking field notes and for tape-recording the interviews. Both the moderator and the observer were experienced nurses working at a coronary care unit and an intensive cardiothoracic surgery care unit, and had cared for dyads with HF for many years. Neither the moderator nor the observer had any care

relationship with the participants and had never met them before the interview. None of the participants had met before the interviews.

To initiate the interviews, all participants were asked to introduce themselves and narrate about how life had changed after the HF diagnosis. Thereafter, questions were asked about what and when information/support was needed and if their needs had changed over time. Other questions focused on whether information/support should be given to the patient and the partner together, or if it should be given individually. Probing questions were asked to gain a deeper understanding and for clarification when needed.

At the end of each interview, the observer verbally summed up what had been said, based on the field notes. This was done to give the participants the opportunity to confirm that everything had been correctly understood and to offer an opportunity to clarify any ambiguities or add information [115]. After the interviews, the moderator and the observer added information to the notes about the atmosphere in the group during the interview. The field notes were used to supplement the transcription during the analysis.

Table 5. The interview guide used during the focus group interviews

- | |
|---|
| <ul style="list-style-type: none"> • How has your life changed as a result of the heart failure? • Do you experience any difficulties managing the heart failure, and if so, what are the difficulties? • What is required for you to feel that you have more control of the heart failure? • What information/support would you like to have? • When should education/support be given? • Does the need for information and support change over time? • Do you prefer receiving education/support together with your partner, or should it be given individually? |
|---|

Data analysis

Statistical analysis

Descriptive statistics were performed to describe the sample with absolute frequencies (n) and %. Depending on the level and distribution of data, group comparisons were tested by chi-square statistics, Fischer's exact test, Mann-Whitney U- test, or Student's t-test (I, II).

Linear regression analyses were conducted to determine the effect of the intervention on health, symptoms of depression, and perceived control (I). For each outcome variable, the difference in scores between baseline and the 24-month follow-up was used as dependent variable, whereas group affiliation (intervention or control) was used as an independent variable. In these analyses, both patients and partners were included together at the same time. Based on the hierarchical structure with patients and partners nested in dyads, regression analyses with robust variance estimates were used [116]. Linear regression analyses were also conducted on patients and partners separately. The results were analysed using intention-to-treat analysis including all randomised dyads.

To test if the patients or partners in the intervention group had less morbidity compared to the control group, independent sample t-test was used for continuous variables. For categorical variables, chi-square test was used (I-II).

To evaluate the long-term effect of the intervention on the different indices in the caregiver burden scale (II), the difference in score between the baseline assessment and the 24-month follow-up was compared between the intervention and control group using independent sample t-test. Cohen's d effect size ($M_1 - M_2 / SD_{\text{pooled}}$, where $SD_{\text{pooled}} = \sqrt{[(SD_1^2 + SD_2^2) / 2]}$) was calculated to estimate the importance of the difference [117]. Cohen's d effect size is an effect size used to indicate the standardised difference between two means. The following

recommendation for interpretation of the effect size was used; small effect 0.20, medium effect 0.50, and large effect 0.80 [118].

To explore changes in caregiver burden from baseline to the 24-month follow-up, partners from both groups were pooled and analysed, using dependent sample t-test (II). All partners from both the control and intervention groups who reported decreased or maintained level of caregiver burden during the follow-up period were compared with those who reported increased caregiver burden, using students' t-test and multiple binary logistic regressions. Variables that were significantly associated with caregiver burden in the univariate analysis were included in multiple binary logistic regressions. Caregiver burden, the outcome variable, was dichotomised into decreased/maintained burden (coded as 1) and increased burden (coded as 0) for all five indices; general strain, isolation, disappointment, emotional involvement, and environment. Factors known from the literature to affect caregiver burden were included as independent variables in the models. The included variables were partner age, gender, education level, patient and partner comorbidity, NYHA-classification, depressive symptoms, perceived control (CAS), physical component score (PCS), and mental component score (MCS) (SF-36) in patients and partners. The regression models were evaluated using the Hosmer-Lemeshow goodness-of-fit test.

The Kaplan-Meier survival analysis was used to examine the distribution of time between the first event, number of days to readmission, or death among the patients or partners (I, II). The log-rank test was used for comparing the Kaplan-Meier curves between the control groups and intervention groups [117].

Missing data in the SF-36 was imputed by means of the subscale if only one item in the subscale was missing. In other instruments, missing data

was not replaced as the constructors did not recommend this (I, II). The level of statistical significance was set to $p < 0.05$. The analyses were conducted using SPSS 18 for Windows (SPSS Inc, Chicago, IL, USA), and Stata 12.1 for Mac (Stata Corporation, College Station, TX, USA).

Qualitative analysis

Data from the nurses' documentation (III) and the focus group interviews (IV) were analysed with qualitative content analysis. Qualitative content analysis can be used to analyse different kinds of text, such as interview transcripts or written documents [119]. This approach was considered applicable to reach an increased understanding of the phenomenon of dyads' supportive needs described both during the intervention and during the interviews, and to describe to what extent the needs were met during the intervention.

The analysis of the nurses' handwritten documentation (III) followed a direct deductive approach, meaning that the analysis used Stuijbergen's model [96] as guidance for initial coding [120]. The direct analysis was chosen to validate the health promotion model used as an inspiration to the intervention [120]. The researchers started with developing operational definitions on the categories. This was done as a discussion between the authors. These predetermined categories were then used as a coding scheme to code the text [120]. A coding scheme is a guide or "translation device that organizes data into categories" (Hsieh & Shannon, 2005, p. 1285). The coding scheme for study III was based on the areas in the dialogue guide, i.e., 1) cognitive components 2) supportive components 3) behavioural components, which were developed from the model, Figure 4.

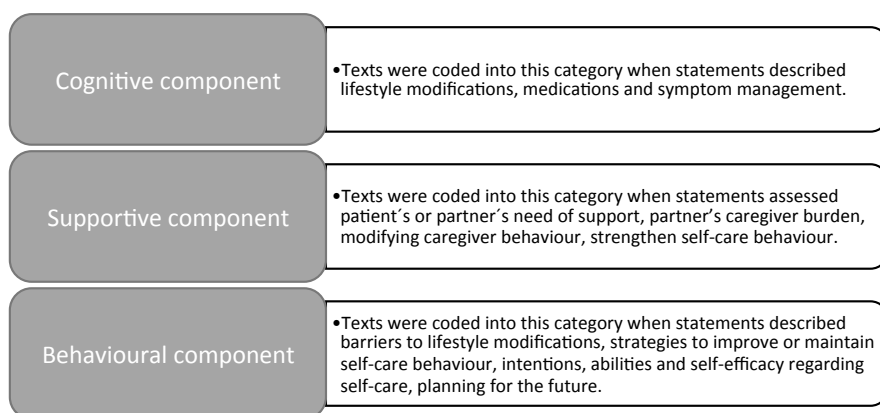


Figure 4. Coding scheme of the predetermined categories, based on the conceptual health promotion model (III).

Secondly, the nurses' documentation from all dialogue guides was typed and made into a clean copy by the author. To obtain a sense of the whole, the text was then read through several times by all authors and text that described cognitive, supportive or behavioural components was marked in different colours and sorted into the appropriate predetermined category. All documentation was validated to be a part of the predetermined categories or to present findings that were new and unknown [120]. Each category was then reviewed and the content was divided and sorted into what was considered to be barriers, resources or self-efficacy, which are the concepts in the model. Finally, there was a comparison to see to what extent the data was supported by Stuijbergen's model [96], or if parts of data represented needs not described in the model.

Qualitative content analysis as described by Graneheim and Lundman [121] was used to explore the perceived caring needs in patient–partner dyads affected by HF (IV). Eight focus group interviews were performed, but no new information was derived after six interviews. Therefore, the

sample of 19 dyads was judged to be large enough to give a variety of experiences, which was also confirmed during the analysis.

A secretary transcribed all interviews verbatim and the author validated the transcripts against the audio-recordings. Field notes from the interviews were used to supplement the transcription with descriptions of the tone of the speaker's voice, body language and interactions between the participants.

The analysis was performed in several steps. First, the text was read several times by all members in the research team to get a grasp of the data as a whole. The author then divided the text into domains, based on the questions in the interview guide. The text in each domain was condensed into meaning units, each comprising of several words, sentences or paragraphs containing aspects related to each other through their content and context. Each meaning unit was labelled with a code at a low level of abstraction. The codes were compared for differences and similarities and sorted into subcategories. The subcategories were examined for underlying meanings. Threads of meaning recurring in different subcategories were formulated into categories representing the manifest content, and the categories were abstracted and formulated as themes representing the latent content.

The analysis was performed as an ongoing dialogue between the authors during the different steps of the analysis to ameliorate the influence of the researchers' preunderstanding (III, IV). This was considered important as all members in the research team are experienced HF nurses and have worked with patient-partner dyads with HF for several years.

Ethical considerations

The studies were designed in accordance with, and followed the World Medical Association Declaration of Helsinki [122] and the Code of Ethics for Nurses [123]. This means that the studies were performed according to the principals of autonomy and with respect for human rights.

Permission to conduct the studies (I- IV) was granted by the Regional Ethical Review Board in Linköping (Study code 03-568 and study code M178-04).

All dyads received verbal and written information about the studies and those who chose to participate gave written informed consent before entering the study. The participants were informed that they could discontinue their participation at any time and that this would in no way affect further care. All obtained study material was coded and stored safely and only available to the research team.

Risks and burden of participation and vulnerability of patients and partners were considered in the study designs. Data collection was performed by questionnaires (I, II), the nurses' written documentation (III), and focus group interviews (IV). An ethical consideration was how burdensome it would be to answer the questionnaires (I, II). It can be tiresome to answer long surveys for participants who are unwell. The choice of instruments and number of questions was therefore carefully considered. Study nurses delivering the intervention were informed that their documentation would be analysed (III). During the intervention the study nurses were instructed to offer the participants contact with a social worker or the HF clinic if participants needed further medical or emotional follow-up (I, II).

The interviews (IV) were guided by respect and sensitivity to the participants, and the author and the observer who did not participate in the patient's care carried out the interviews.

In study I-III participants were guaranteed confidentiality. In study IV participants introduced themselves by their first name and could choose if they wanted to share more personal information with the other participants in the focus group. During the focus group interviews, both the moderator and the observer were observant of any signs of discomfort in the participants. They also had time to speak individually with the participants after the interviews and answer any questions and concerns.

All participants also had contact details to the research team if they wanted to get in contact about any concerns they might have.

RESULTS

Study participants

155 patient-partner dyads participated in the intervention; 71 patients (I, III) and 71 partners (I-III) in the intervention group, and 84 (I) patients and 84 partners (I, II) in the control group. The mean age for the patients was 69 (SD=14) years and partners 67 (SD=12) years. Sixty-nine per cent of the patients were male and 55% were in NYHA-class III. Regarding employment, 14% of the patients and 33% of the partners worked full time, 86% of the patients and 64% of the partners were retired/on sick leave, and 3% of the partners were homemakers.

Of the 49 dyads invited to participate in the focus group interviews (IV), 19 agreed to participate. Reasons given for not participating were; feeling too ill and/or fatigued, a sick spouse, or disinterest. Nineteen patients (7 females/12 men) and 19 partners (12 females/7 men) were included. The patients' age ranged between 55-89 years and the partners' age ranged between 48-87 years. The majority of the patients were in NYHA III and were diagnosed with HF between the years 1990-2009.

Baseline clinical and demographic characteristics of the dyads in all studies are described in Table 6 (I-IV).

Table 6. Clinical and demographic characteristics of the dyads included in the control group and intervention group in study I-IV. A flowchart of all studies is presented in Figure 3.

	Control		Intervention		Focus groups	
Characteristics	Patient (n=84) (I)	Partner (n=84) (I,II)	Patient (n=71) (I, III)	Partner (n=71) (I-III)	Patient (n=19) (IV)	Partner (n=19) (IV)
Female, n (%)	16 (19.1)	68 (80.9)	22 (30.9)	49 (69.1)	7 (37.0)	12 (63.0)
Age, mean±SD	72.9±10.4	69.5±10.1	69.4±13.6	67.1±12.1	68.7±9.1	66.5±10.4
NYHA, n (%)						
II	25 (29.8)	—	24 (33.8)	—	7 (36.8)	—
III	43 (51.2)	—	40 (56.3)	—	8 (42.1)	—
IV	16 (19.0)	—	7 (9.9)	—	4 (21.1)	—
Medical history, n (%)						
Myocardial infarction	38 (45.2)	13 (15.5)	23 (32.3)	8 (11.3)	7 (36.8)	0
Hypertension	26 (31.0)	25 (29.8)	27 (38.0)	25 (35.2)	5 (26.3)	4 (21.1)
Diabetes	10 (11.9)	4 (4.8)	8 (11.3)	7 (9.9)	1 (5.2)	1 (5.2)
Stroke	8 (10.0)	4 (4.8)	9 (12.7)	3 (4.2)	2 (10.5)	0
Lung disease ^a	7 (8.3)	10 (11.9)	3 (4.2)	1 (1.5)	0	3 (15.8)
Medication, n (%)						
ACEI/ARB	76 (90.5)	—	65 (91.5)	—	19 (100.0)	—
β-blockers	74 (88.1)	—	62 (87.3)	—	16 (84.2)	—
Diuretics	63 (75.0)	—	56 (78.9)	—	15 (78.9)	—
Education, n (%)						
Elementary school	56 (66.7)	48 (57.1)	40 (56.3)	41 (57.8)	12 (63.2)	10 (52.7)
High school	21 (25.0)	22 (26.2)	22 (31.0)	26 (36.6)	5 (26.3)	9 (47.3)
University	7 (8.3)	14 (16.7)	9 (12.7)	4 (5.6)	2 (10.5)	0
Employment, n (%)						
Full time	10 (11.9)	18 (21.4)	10 (14.1)	22 (31.0)	3 (15.8)	5 (26.3)
Disability pension/sick leave	10 (11.9)	4 (4.8)	13 (18.3)	2 (2.8)	4 (21.1)	0
Retired/Homemaker	64 (76.2)	62 (73.8)	48 (67.6)	47 (66.2)	12 (63.1)	14 (73.7)
Lifestyle, n (%)						
Smoking/ Ex-smoking	47 (56.0)	39 (46.4)	36 (50.7)	30 (42.3)	10 (52.6)	9 (47.3)
Alcohol Never drink	20 (26.0)	18 (23.4)	16 (23.9)	16 (23.9)	4 (21.1)	3 (15.8)
≤7 glass/week	54 (70.1)	57 (74.0)	45 (67.1)	46 (68.7)	14 (73.7)	13 (68.4)
>7 glass/week	3 (3.9)	2 (2.6)	6 (9.0)	5 (7.4)	1 (5.2)	3 (15.8)
BMI, mean±SD	26.8±4.1	26.9±4.2	26.6±4.5	26.6±4.9	27.83±4.5	26.2±3.6
Instruments (baseline scores)						
PCS, mean (SD) ^b	38.4 (12.4)	44.4 (11.3)	41.5 (11.8)	48.7 (9.4)	—	—
MCS, mean (SD)	44.0 (12.6)	46.0 (12.4)	43.2 (12.1)	46.4 (10.4)	—	—
BDI, mean (SD)	9.8 (8.4)	7.95 (7.6)	9.5 (8.0)	6.88 (5.6)	—	—
CAS, mean (SD)	16.6 (4.6)	17.32 (4.7)	15.2 (5.3)	14.79 (5.6)	—	—
CBS, mean (SD)	NA	1.8 (0.5)	NA	1.7 (0.5)	—	—

^aLung disease was significantly ($p < 0.05$) more common in the partner control group compared to the partner intervention group.

^bPCS baseline scores was significantly ($p < 0.01$) higher in the patient/partner intervention group compared to the control groups (I,II). NYHA class = New York Heart Association Functional Classification, ACEI = Angiotensin-Converting Enzyme Inhibitors, ARB = Angiotensin Receptor Blocker, β-blockers = Beta blockers,

Dyad reported outcomes

Dyads lost to follow-up (I, II)

Study I and II explored the 24-month effect of a psycho-educational intervention delivered to patient-partner dyads. All dyads attended all three sessions of the intervention, but as shown in Figure 3, a total of 59 dyads did not complete the 24-month assessment.

During the follow-up period, the all-cause mortality rate for patients in the intervention group was 17% (n=12) and 26% (n=22) in the control group. One partner in the control group died during the 24-month follow-up. A total of 15 dyads in the intervention group and 9 in the control group reported to be too frail or sick to complete the questionnaires at 24 months. There were no significant differences between the responders and non-responders regarding age, gender, education or employment, neither in patients or partners. The 24-month assessment was based on 44 dyads in the intervention group and 52 dyads in the control group.

Long-term effects of the intervention

The results showed that the intervention did not have any significant effect on physical or mental health- related quality of life, depressive symptoms, or perceived control over the HF among the dyads after 24 months (I), Figure 5.

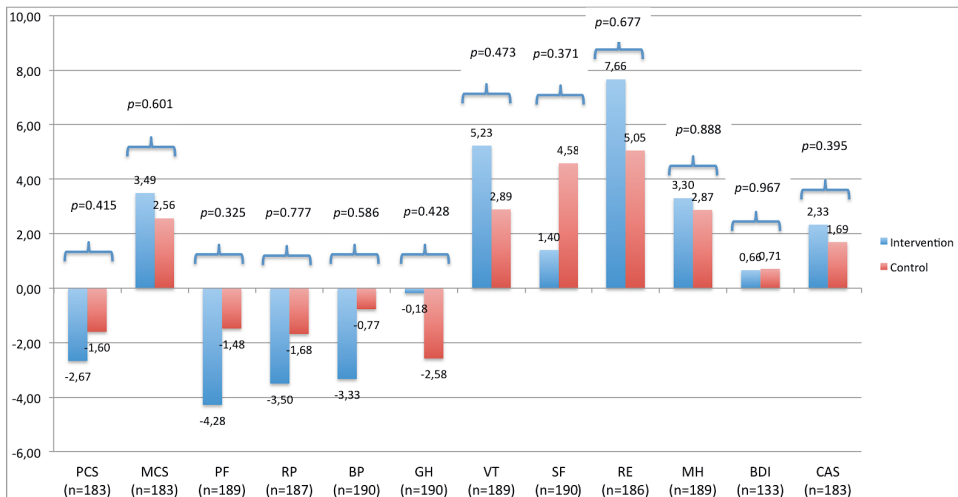


Figure 5. Mean difference between the baseline and 24-month follow-up assessment for both patients and partners.

To explore if the intervention had specific effects on patients or partners, regression analyses were conducted on each group separately. The analyses did not show any significant differences between the patients in the intervention and control group. As for the partners, both the intervention and control group reported decreased physical health between baseline and the 24-month assessment. However, those in the intervention group had a significantly greater decrease in both PCS ($B = -4.13$, $t(90) = -2.43$, $p < 0.05$), and physical functioning ($B = -6.76$, $t(93) = -2.21$, $p < 0.05$).

Dyad events

The Kaplan-Meier curves did not differ between the patients and the partners in the intervention group and the control group with regard to time to first readmission/death; patients ($\chi^2(1) = 1.10$, $p = 0.293$), Figure 6, partners ($\chi^2(1) = 2.48$, $p = 0.115$), Figure 7.

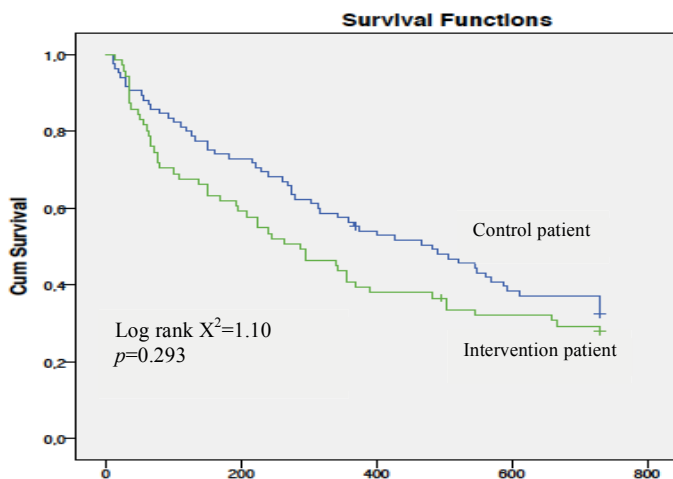


Figure 6. Days to first event for the patients in the intervention group and the control group.

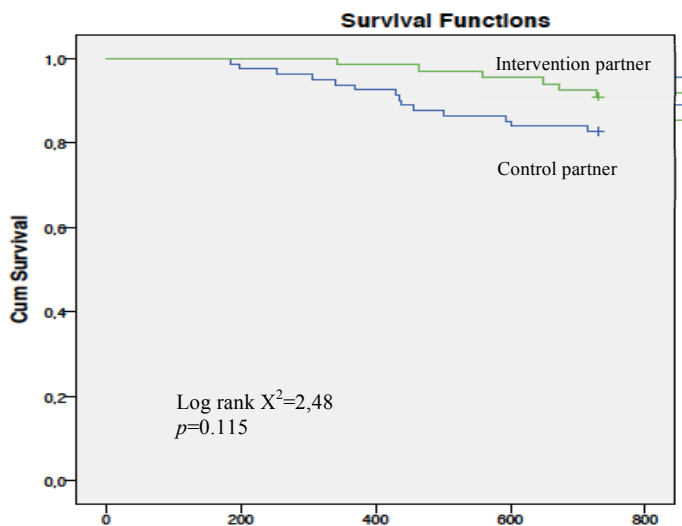


Figure 7. Days to first event for partners in the intervention group and the control group.

There was no significant difference between the patient groups regarding readmission within 24 months, which occurred in 72% (n=51) of the patients in the intervention group and in 69% (n=58) in the control group ($p=0.721$). In the control group, 77% of readmissions were due to heart

failure or heart disease. In the intervention group, this number was 87% ($p=0.520$).

Regarding partners, 13% ($n=9$) in the intervention group and 22% ($n=19$) in the control group were hospitalised during the 24 months ($p=0.141$). There was no difference in number of hospital admissions among partners in the groups during the 24 months ($p=0.201$), or in days to first admission.

Caregiver burden in the partners

There were no significant differences between the partners in the intervention group and in the control group in any dimension of caregiver burden after 24 months (II), Table 7.

Table 7. Mean difference in caregiver burden baseline–24 month between control group and intervention group.

	Control (SD) $n=52$	Intervention (SD) $n=44$	p -value ^a (2-tailed)	Cohen's d effect size
Total caregiver burden	0.08 (0.36)	0.10 (0.46)	0.803	0.05
General strain	0.17 (0.49)	0.15 (0.55)	0.887	0.03
Isolation	0.75 (0.67)	0.03 (0.56)	0.727	0.07
Disappointment	0.05 (0.52)	0.05 (0.61)	0.935	0.02
Emotional	0.16 (0.67)	0.02 (0.50)	0.251	0.11
Environment	0.15 (0.72)	0.34 (0.70)	0.210	0.26

^a Independent sample t-test

When analysing the partners in the intervention group and control group together, the results showed that the total caregiver burden had increased significantly after 24 months, compared to baseline (1.65 ± 0.55 vs 1.73 ± 0.64 , $p<0.049$, $d=0.14$). General strain was perceived as being the most burdensome and increased over time (1.71 ± 0.62 vs 1.87 ± 0.69 , $p<0.004$, $d=0.24$), as did burden related to environment (1.54 ± 0.56 vs 1.79 ± 0.74 , $p<0.002$, $d=0.37$). The indices related to isolation and disappointment did not change over time. The emotional index decreased

significantly after 24 months (1.57 ± 0.68 vs 1.44 ± 0.64 , $p < 0.046$, $d = 0.21$) (II).

Twenty-one partners (50%) in the intervention group, and 19 in the control group (47%) reported decreased or maintained caregiver burden after 24 months. The logistic regression models showed that younger age in the partner was associated with decreased/maintained general strain ($OR = 0.95$, $p = 0.038$, $d = 0.36$). Higher perceived control over the HF in patients was associated with decreased/maintained caregiver burden in relation to disappointment, including loneliness, physical, and financial burden ($OR = 1.11$, $p = 0.033$, $d = 0.44$). Better mental health in the partner was associated with decreased/maintained caregiver burden in the environment dimension, indicating a better management of practical problems related to caregiving ($OR = 1.05$, $p = 0.046$, $d = 0.54$) (II).

Dyads' perceived caring needs

The intervention was inspired by a health promotion model, which was used as a frame when analysing the nurses' documentation (III). The intervention was composed of three components, 1) cognitive components 2) supportive components, and 3) behavioural components, and the content in each component was divided into what was found to be barriers, resources and self-efficacy. The analysis confirmed the coverage of all the components in the nurses' documentation (III), and the documentation and the focus group interviews (IV) revealed a wide range of perceived cognitive, supportive and behavioural caring needs among the dyads. The focus groups disclosed two themes; Dyads perceive a need for continuous guidance through the different phases of the illness trajectory, and Dyads perceived a need to share burden and support with each other and other dyads (IV).

Dyads' cognitive needs

During the first intervention session nurses' documentation described that the dyads needed to gain knowledge about HF and self-care management, even if they had lived with the diagnosis for several years. Some patients had not really understood that they were sick and the lack of insight meant that they had not engaged in self-care activities. As for the partners, almost none had felt invited to the patient's healthcare visits, medical appointment or visits to the nurse-led HF clinic. Therefore, they had no prior knowledge and had not been involved in or encouraged the patient's self-care activities (III). Some dyads had tried to seek disease-specific information on the Internet, but found it difficult to find web pages with simple and reliable information (III, IV).

The dyads described a need to learn about the disease, self-care and prognosis, and also about practical things, such as how to act and who to contact in case of deterioration (III, IV). The intervention brought up many thoughts that required support from the nurse in order to process (III). During the sessions, the dyads enhanced their knowledge and became more confident in handling their situation. The patients had built up their confidence to engage in self-care activities, and both patients and partners had gain preparedness in how to act in everyday life in case of deterioration, and how deterioration could be prevented (III).

Dyads' supportive needs

Supportive needs were described as a wish for support from different directions, both from healthcare professionals, from each other and from other dyads in the same situation (III, IV). The need of support from healthcare professionals was substantial during the immediate period after the diagnosis, but continuous support and guidance was also viewed as important during the illness trajectory (III, IV). The need for joint patient-partner participation during hospital appointments was highlighted, because the disease affected them both. When only patients

attended the visit they found it difficult to remember all the information and recalling it to their partner. The partners also had questions, but without knowledge their understanding on how to support and assist the patient was limited (III, IV). The nurse at the HF clinic was described as the only healthcare professional who also took an interest in the partner's well-being, and offered support to the partner (IV). Dyads emphasised the need for trustful and long-term caring relations with healthcare professionals also after the intervention had ended (III, IV). The sessions at the nurse-led HF clinic and the possibility to get in contact with the nurse during the daily telephone hours increased the feeling of security (III, IV).

Dyads supported each other and shared the chores on the basis of strength and ability. With increased knowledge, they described an increased understanding of why self-care activities are important, and for some patients this led to the insight that they needed support from their partner. Partners wished to learn and become more involved in the daily care, but they also tried to encourage the patients to take responsibility for managing the HF (III, IV).

Several of the dyads requested nurse-led support groups with other dyads in the same situation to share experiences (IV). Some participants, especially the partners, suggested that the group sometimes should be divided into separate patient and partner groups. Some issues were found to be difficult to discuss in a joint group with both patients and partners, for example prognosis, but in separate groups, an opportunity would be provided to address issues that each group perceived as particularly difficult to talk to each other about (IV).

Dyads' behavioural needs

Being affected by HF meant that many adjustments needed to be done to adapt to the new situation. Patients could no longer socialise like before, and therefore, the partner had less social interactions. The dyads easily

became isolated, as the partner did not want to leave the patient alone and had to take over more of the workload in the household (IV). The additional burden was described as mentally exhausting for the partners due to a greater responsibility (III, IV). The new roles sometimes led to conflicts in the relationship. Patients sometimes felt overprotected when the partner set physical limits to avoid the patients from overstraining (III, IV). Partners, in turn, described feelings of hopelessness and disappointment that life had not turned out the way they had hoped. Life constantly revolved around the patient and his/her needs, which made the partners feel tired, isolated and dejected. They also carried a sense of guilt when they sometimes attended social activities alone (IV). During the discussions the dyads needed the nurses' help to guide them to communicate their thoughts and concerns with each other, and the nurses also helped them to plan for the future (III). Sometimes, the dyads realised that some adaptations had to be made, for example, change of accommodation or the partner's employment (III, IV). For some dyads, the new roles had strengthened the relation and they collaborated with and provided mutual support to each other (III).

Comprehensive interpretation of the caring needs in relation to the psycho-educational intervention

The overall aim of this thesis was to evaluate the effects of a dyadic HF intervention during long-term follow-up, and explore the dyads' perceived caring needs. Being affected by HF was described as a major transition in life for both patients and partners (I- IV). The total caregiver burden in both groups of partners increased from a moderate burden at baseline, to a moderate to severe burden after 24 months. Especially older partners, partners with bad mental health, and dyads where the patients had low control over the HF were found to have an increased caregiver burden

over time (II). The intervention did not have any long-term effect on physical or mental health, depressive symptoms, or perceived control over the HF among the dyads after 24 months (I). The qualitative findings have shed some light on what needs to be more clearly emphasised in future dyadic interventions. Gaining knowledge and having trustful long-term relations with healthcare professionals had a prominent role in the dyads' descriptions of their supportive caring needs (III- IV). The intervention period extended over 12 weeks, which the dyads found to be too short. Furthermore, the dyads wished for easy access to healthcare professionals (III- IV). During the intervention the dyads had a telephone number and could contact the nurse when needed (I). This opportunity did not remain after the intervention period was over. The intervention used a dyadic approach during the session, and both the patient's and the partner's caring needs were discussed. However, they had no contact with other dyads in the same situation, which was a need that emerged during the qualitative analyses (III- IV).

During the intervention, patients and partners participated as equals and were free to discuss whatever issues they felt to be important. The nurses helped the dyads to discuss relational difficulties if needed, but the intervention did not specifically emphasise relational issues, which was found to be important aspects of the dyads' caring needs (III- IV). When the intervention was over, they did not have anyone to help out when difficulties arose (IV). The comprehensive interpretation suggests revising Stuijbergen's model and including long-term support as a new concept when using the model in patients with HF and their partners.

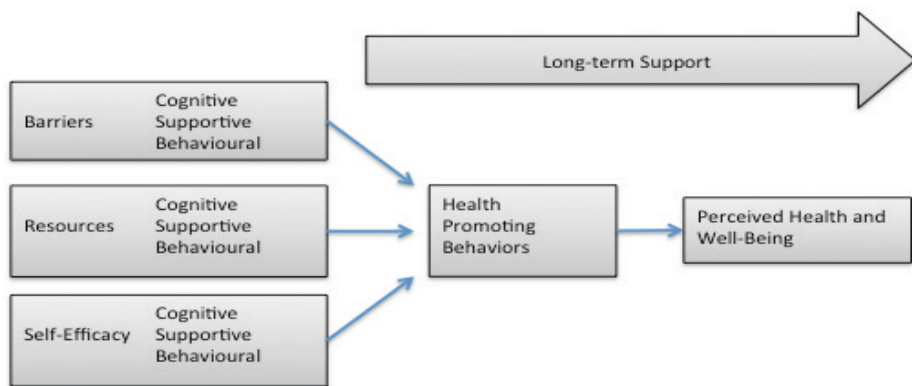


Figure 8. The conceptual health promotion model including long-term support as a new concept.

DISCUSSION

Discussion of the results

To our knowledge, there are no previous studies in the HF population that have evaluated the effect of a dyadic intervention up to 24 months. The uniqueness of this study was that the intervention was based on a model and patients and partners participated as equals throughout the study. The fact that data was analysed also on a dyadic level is rare (I, II). Doing a dyadic analysis instead of separate analyses for the patient and partner was one way of controlling for interdependence. To fully understand what the dyads' long-term caring needs were and what the intervention was missing, the nurses' documentation in the model-based dialogue guide used during the intervention was analysed (III). Finally, focus group interviews with dyads from both the intervention group and control group were performed (IV).

Long-term effects of the dyadic intervention

Despite a well-structured, model-based intervention, the effect of the 24-month follow-up period was neutral (I, II). The reason for this is probably multifaceted. One reason could be a ceiling effect as all patients received evidence-based medical treatment and structured follow-up at a nurse-led HF clinic in the standard care. This is known to decrease morbidity and mortality [1, 124], and therefore made it hard to further improve outcomes. Another explanation might be a lack of contrast, caused by the fact that some partners in the control group may have accompanied the patient to their appointments at the nurse-led HF clinic (I, II).

The level of depressive symptoms in the patient groups was also low both at baseline and at 24 months, which made it hard to improve outcomes. Furthermore, patients in both groups experienced fairly low perceived control at baseline, which improved to a moderate level during the follow-

up period. It is known that patients often experience an increase in symptom burden, such as depressive symptoms, over time [125], and maybe the fact that perceived control improved helped to maintain depressive symptoms low also after 24 months (I). Patients with higher levels of perceived control have been found to experience fewer symptoms of depression compared to patients who experience lower levels of perceived control [112].

Another reason for the lack of effectiveness of the intervention could be that the content may not have been sufficient and fully addressing all the individual dyads' needs (I, II). Nursing interventions addressing psychological needs in dyads with coronary heart disease have shown only modest improvements in patients' HRQoL, knowledge of disease and treatment, and in partners' anxiety, knowledge and satisfaction with care, and no effect on the dyads' depressive symptoms [18]. However, during the sessions a variety of needs were discussed and the nurses' documentation revealed that the dyads' knowledge and confidence increased during the time of the intervention (III). Self-management interventions have been found to improve HRQoL for up to 12 months in patients with HF, but standardised designed education also influences HRQoL negatively [126], so it seems clear that one type of intervention does not fit all dyads. To improve outcomes, individualised and more targeted interventions, addressing both practical and mental components, are probably needed.

An insufficient intensity of the intervention (too short or too few sessions) may also explain the lack of effect (I-II). Earlier studies have found that shorter interventions might not be enough to change outcomes [127]. Patients in the intervention group scored higher levels of perceived control at the 3-month assessment [102], but the same result was not found after 24 months (I). The dyads highlighted the need for long-term

support, which confirms the need to extend the intervention period (III, IV). Studies that have used longer intervention periods for a variety of different chronic or severe illnesses have been found to be more effective [128-130]. For the dyads to be able to perform self-care management, the need for continuous guidance through knowledge acquisition was emphasised (IV). Dyads sharing the responsibility for the care report better overall self-care management [8].

When designing interventions it is important to take into account that dyads are likely to manage HF care the same way as they have managed complex situations in the past and according to established patterns developed over the trajectory of their relationship [131]. To better understand how to support HF dyads, different dyadic care types have been described. There is the *Patient or Caregiver oriented type*, where either the patient or the partner takes care of the HF self-care, or the *Collaboratively or Complementarily oriented dyads*, where they collaborate or take care of different aspects of the self-care. Based on that, an instrument has been developed to help healthcare providers to identify dyadic care types. The instrument could be helpful for understanding how different dyads relate to self-care and guide individualised support [131].

In the RCT study, only the patient and the partner was included (I), and including other family members as well can be one way to achieve better outcomes [132, 133]. Sometimes the whole family need support from nurses to find their way toward well-being. Healthcare professionals need to listen to families' stories of illness to become aware of what beliefs may support and encourage family well-being and healing [134]. In cardiovascular care, family-based approaches including both partners and children have been found to encourage communication in the family unit. Addressing the structural and environmental conditions in which families live could be the most effective approach to promote cardiovascular health [135]. A broader approach where patients choose the participating

caregiver may be beneficial. If patients select the person he or she wants to be included in the care, the effects from interventions might improve, as people living together are not always the ones supporting each other.

Caregiver burden in the partners

Being a caregiver imposes a substantial burden that increases over time and affects partners' HRQoL (II- IV). However, we were not able to decrease the caregiver burden among the partners by the intervention (I, II). As partners in both groups reported a significant increase in total caregiver burden, general strain, and burden related to environment after 24 months, this underlines the importance of finding ways to strengthen the partners' situation during the illness trajectory (II).

It is not the patient's diagnosis or severity of the illness that has been found to correlate with caregiver burden, instead it is the caregiver's resources, which may be enhanced by successful coping styles. An anxious coping style where the dyad experiences low control increases the risk for depressive symptoms and poor mental well-being in the partners [136]. Better mental health in the partner was associated with decreased/maintained environmental burden, indicating a better management of practical problems related to caregiving (II).

The intervention aimed to increase the dyads' self-efficacy and give them resources to cope with everyday life (I). Self-efficacy mediates the relationship between depression and adherence to self-care. This indicates that interventions aiming at increasing the patient's self-efficacy may have greater impact on self-care adherence than interventions targeting depression or HRQoL [15, 137]. By increasing the patient's self-efficacy, he/she may experience improved perceived control and by that, partners' caregiver burden can be reduced. The current study aimed to increase self-efficacy in both patients and partners, but maybe three sessions was not sufficient to reach this goal.

Placing the current results in the context of other studies, future interventions might be more effective if relational aspects are included. Living with HF was described as a constant concern for the present and the future (IV). Both patients and partners felt that the stress led to changes in mood and shorter temper. That, in turn, led to more conflicts between them, and these conflicts were something they had not experienced before. Not being able to talk to each other as before created uncertainty (III, IV). Several studies have emphasised the importance of including and measuring relational aspects in dyadic interventions [128], as good marital quality has been found to significantly improve survival in patients with HF [138]. Dyadic interventions, regardless of the patient's diagnosis, enhance partners' psychological functioning (i.e., self-efficacy, stress, and anxiety), and perceptions of marital quality and coping as a couple, favouring dyadic intervention over usual care or interventions addressing only the patient [130, 139, 140].

Dyads' needs of supportive care

As there was a neutral long-term effect of the intervention, the aim in study III and IV was to gain more in-depth knowledge about how well the health promotion model suited, and learn about the dyads' perceived caring needs. The dyads agreed that it is important for both the patient and partner to receive information (III, IV), but it is known that healthcare professionals mainly invite only the patient to the outpatient clinic visits [56]. Active partner participation can enhance self-care behaviours and increase both patients' and partners' perceived security [141]. Partners often play a key role in the care at home, but when the patient becomes hospitalised or needs to seek care, partners often find themselves playing the 'second fiddle', and the possibility to influence decisions and take an active part in the care is reduced [142].

Healthcare professionals need a different approach, where they recognise partners and family members as important actors in the care of the

patient. Including partners in the care facilitates patients and partners sharing the care in everyday life. Partners play a key role in supporting the patient at home, so the patient and the partner need the same information and an opportunity to ask questions (III, IV). Maybe patient navigator nurses often used in cancer care could be beneficial also for dyads with HF. Navigators in cancer care assess patients' needs and collaborate with the patient and their families to develop plans to overcome barriers, offer emotional support and assistance with information needs, problem-solving, and logistical aspects of cancer care coordination [143, 144]. Patients with cancer describe the navigators as a person "being there" [143], which was the same as what the HF dyads asked for. They wished for long-term support from healthcare professionals they knew and felt secure with (IV).

Several of the dyads emphasised the need to share concerns and experiences with other dyads in the same situation. Support groups are frequently used in the rehabilitation after a myocardial infarction, but they are not so common in the care for patients with HF and their partners [145]. Group sessions could fill several needs for the dyads as support groups can provide a sense of validation, relief and comfort, as well as overcome social isolation [145, 146]. Partners described feelings of hopelessness and disappointment that life had not turned out the way they had hoped. They watched over their loved ones day and night, which made them feel tired and isolated. They also carried a sense of guilt when they sometimes put their own interests first and attended social activities alone. Patients also became isolated when they did not manage to socialise like before (III, IV). Exchanging experiences with dyads in the same situation in groups where healthcare providers also take part provides an opportunity to learn both from other dyads and from professionals (IV). By attending support groups, dyads could support each other and discuss how to handle difficult situations, and partners could

also be supported to make demands on the patient to help with simple chores. This type of intervention was recently tested, with the aim to determine the effectiveness of a supportive educative group intervention for reducing family caregivers' burden [91]. The findings indicated a significant reduction of the family caregivers' burden in the intervention group and an increase in the control group.

Caregiver burden increased in both groups during the 24-month follow-up (II). Partners who experience higher caregiver burden may need psychosocial and supportive interventions the most, but find it difficult to prioritise these needs and also to leave home without the patient. Caregivers of patients with severe HF symptoms spend more time supporting the patient and experience more difficulty performing caregiving tasks [147]. Perhaps e-Health interventions would be feasible for these partners. These have been found to be both effective and cost-effective in somatic diseases [148]. Online education, counselling, and support as a complement to nursing visits, may be beneficial when partners or dyads have difficulties leaving home.

Methodological considerations

The studies in this thesis combined both quantitative and qualitative methods. Collecting data from different sources and with different methods could be considered to strengthen the result [119]. The benefit of a quantitative approach is the possibility to measure the reactions of a large number of participants, make comparisons between groups and statistically analyse the data, which makes it possible to generalise the findings to similar populations. On the other hand, qualitative methods give detailed information about a smaller number of participants, which increases the depth of understanding of the people and situation studied

[119]. Depending on whether the research approach is qualitative or quantitative, there are different aspects of the constitution of rigour, and to ensure scientific rigour in the thesis different steps were taken [149].

Sample

Study I and II used a randomised controlled design. Randomised controlled trials (RCT) are very well suited for drawing conclusions on the effect of healthcare interventions [104]. These studies measured the effect of a dyadic intervention and a power analysis was conducted before the study started (I, II). A sample size of 108 dyads was expected to be sufficient, but given that the dropout frequency was expected to be high during the 24-month follow-up, 155 dyads were recruited. A large sample size leads to increased precision in measurements and the study detecting an effect of a specified size [117].

The recruitment of dyads was challenging, and the period for inclusion extended over three years. However, during this time period, there were no changes in the recommendation regarding treatment of HF in the guidelines. Random allocation gave all dyads the same chance to be allocated to either intervention or control (I) [117]. There were no significant differences between the control groups and the intervention groups, except for the fact that lung disease was significantly ($p < 0.05$) more common in the partner control group compared to the partner intervention group.

Many of the eligible patients or partners were too fatigued or marked by illness to participate in this type of intervention that requires an active commitment from both parts of the dyad. This suggests a potential for selection bias in the study sample and it also affected the generalisability, as only 28% of those eligible were randomised. The dyads that chose to participate might have been less burdened than those who chose not to, and dyads choosing not to participate could have been more fatigued or experiencing lower quality of life. Dyads declining participation have been

found in other joint studies as well, and the most common reasons for not taking part were partners not wanting to participate, patients feeling too fatigued or not wanting to put another burden on their partner [150].

There are no specific rules for sample sizes in qualitative studies, but there are recommendations regarding different forms of data collection [119]. In study III, the dialogue guides from all dyads in the intervention group were included in the analysis. A purposeful sampling from study I was selected for inclusion of dyads in the focus group study (IV). In purposeful sampling, data collection is completed when no new information emerge from new sample units [119]. Eight focus group interviews were performed, but no new information emerged after six interviews. To further establish credibility, the sample was made to ensure variation regarding age and gender, and dyads were recruited from both the intervention group and the control group to make observations of the dyads' perceived caring needs. Of the 49 dyads available, 19 agreed to participate.

In all four studies, the majority of the partners were females. The same gender distribution was also seen in a previous study [65]. This could be a result of the patients' mean age of 69 years in the current study (IV) being lower than the average mean age for the HF population, and the fact that onset of HF occurs earlier in men than in women [22].

The intervention

All HF nurses who delivered the intervention were experienced in caring for patients with HF. Prior to the intervention they had attended theoretical and practical training on how to deliver the intervention and how to use and document in the dialogue guides (I- III). The study team regularly assessed the nurses' competence and study fidelity through observations and consultations to ensure that the model was implemented throughout the study, and that the documentation was performed as instructed.

A threat to the internal validity of the study could be that the partners in the control group might also have received support and education when accompanied patients to the HF clinics (I, II). However, during the intervention, partners were seen as the patient's equal, as they were treated as a dyad throughout the whole study, which usual care does not.

Data collection

In quantitative research, aspects of validity and reliability are considered to be of great importance. Reliability refers to the consistency of the measurements and validity is the degree to which an instrument measures what it is supposed to measure [104]. Valid and reliable instruments were used and the scores were handled in accordance with the given instructions (I, II). The large number of items in the questionnaire package could be tiring for elderly people to complete, and maybe the intervention was not fully aligned with the evaluated outcome. In this type of complex interventions it is always a concern not to have chosen sensitive outcomes that mirror the content of the intervention [151]. To limit the number of instruments, measurement of the quality of the relationship between the dyad members was not performed. This would have been interesting to measure at baseline as it may have influenced the way the dyads responded to the intervention (I, II).

Due to the nature of the intervention, the study could not be double-blinded. However, both data collectors and the author entering the data were blinded to group assignment.

To strengthen credibility and confirmability, different strategies were used in the qualitative studies (III, IV). The nurses' documentation was used verbatim and the text varied in depth and length. Some nurses wrote summative and others described the discussions with more words. Nevertheless, all documentation provided important and clear information on the components of dyad functioning as assessed during the sessions (III).

Choosing focus groups instead of individual or dyad interviews may have enriched the results, as the interaction between the participants highlighted different caring needs (IV). Focus group interviews are carefully planned discussions taking advantage of group dynamics for accessing rich information [104]. An interview guide was developed by the research team to ensure that the same topics were explored during the different interviews. However, being interviewed in a group may have been a barrier for some of the invited dyads who therefore chose not to participate, which in turn can be considered as a limitation of the study.

Before the interview started, contact was established through informal conversations where the participants, the moderator, and the observer introduced themselves. This was of importance to make informants feel comfortable and relaxed [115]. At the end of the interview, participants had the opportunity to discuss topics they considered important but were not covered in the interview guide, and the observer's summary gave the dyads an opportunity to correct any misinterpretations. During the interviews, the atmosphere was openhearted and all informants took an active part in the discussions.

Data analysis

Quantitative data was analysed with established statistical methods (I, II). Ninety-six dyads filled out the questionnaires at 24 months, and the sample size calculated the need for 108 dyads (I, II). Therefore, none of the regression analyses included the required sample size determined in the power analysis. This probably did not affect the results as the mean differences between the intervention group and control group were small for all outcome variables (I, II).

Different approaches of qualitative content analysis were applied in two studies (III, IV). The analysis was performed systematically following described steps and could be considered as a strength for credibility [152].

The nurses were informed that their documentation would be analysed. The raw data consisted of handwritten text, but all nurses had a clear handwriting, so all data was credible and included in the analysis (III).

The coding of the first three interviews and the first ten dialogue guides was performed as a dialogue between the author and two researchers in an attempt to ameliorate the influence of the researchers' preunderstanding on the analysis, and to establish a mutual understanding and foundation for the rest of the analysis. Thereafter, the author conducted the analysis, but to ensure trustworthiness, each step of the analysis process was discussed until consensus about the interpretation was reached. Finally, one researcher who had not been closely involved during the analysis performed a critical review of the findings. Furthermore, the findings were compared to findings from previous research. This strengthens the credibility, dependability, and confirmability of the findings (III, IV).

Generalisability and transferability

The randomised controlled trial (I, II) was based on a relatively large sample of dyads affected by HF. Despite more participants being included than supported by the initial power calculation, the dropout was higher than expected at the long-term follow-up due to death and deterioration in the patients. This may lead to us not being able to generalise the findings in the most severely ill and frail dyads.

The patients' age ranged from 30-84 years, with a mean age of 69 (SD=14) years (I, II). This means that the mean age in the study population was lower than in the Swedish HF population [22], which could limit the external validity. This is also mirrored by the fact that the majority of the participating patients were men, and the onset of HF is earlier in men [22]. This may affect the generalisability to the whole group of patient-partner dyads affected by HF, but the result could be generalised to dyads of the same age.

The findings in the qualitative studies describing the use of the healthcare model showed that the model suited for patients with HF and also for their partners (III) and the comprehensive interpretation suggests revising Stuifbergen's model and including long-term support as a new concept when using the model in patients with HF and their partners. In addition, dyads' perceived caring needs (III, IV) could be transferable to patient-partner dyads in a similar context.

Clinical implications

The results from this thesis can be used to further develop the psycho-educational care for patient-partner dyads affected by HF to meet their caring needs. Despite a neutral result of the intervention, the qualitative analysis revealed a variety of perceived caring needs, and it is evident that the dyads' needs must be individually assessed and not assumed. The dyads wanted support and long-term contact with healthcare professionals they had confidence in. This shows the importance of organising care with continuity to build trustful relationships, which provides security and enables the dyads' development of self-care skills. Easy access to a specific healthcare provider during daily telephone hours is also of great importance for both patients and partners in order to feel secure.

Caregiver burden increased significantly after 24 months compared to baseline for all partners. Many partners are involved in the patient's care and have an ongoing need for information and also concerns of their own. Therefore, partners should be invited and welcomed to the patient's healthcare appointments if the patient agrees to joint visits. This facilitates the exchange of care-related information, increases the dyads' ability to perform self-care and decreases the partner's burden not being able to manage practical problems related to the caregiving situation.

There is also a need to test support groups in HF dyads, as they are frequently used in the rehabilitation after a myocardial infarction in order

to overcome social isolation and give relief and comfort during the illness trajectory.

Future research

This thesis has generated new questions for future research and ideas for new interventions about how to support patient-partner dyads with HF.

- Develop and test a longer intervention combining both face-to-face sessions and telephone support where also other family members selected by the patient can be included.
- Develop and test interventions with dyad support groups, both with patients and partners or only patients or partners.
- Develop and test web-based psycho-educational interventions aiming to support the dyads and reduce the partners' burden.
- Health-economic evaluation of cost-effective interventions is needed.
- Further explore how to best support different dyadic care types.
- Explore the relationship between perceived control over the HF, depressive symptoms and well-being in patients with HF and their partners.
- Exploration of patients' and partners' symptoms of depression mediates or moderates the relationship between perceived control and well-being.

Conclusions

- The dyadic psycho-educational intervention did not have a long-term effect on physical or mental HRQoL, depressive symptoms, or perceived control over the HF among the patient-partner dyads, or on the partners' caregiver burden.
- Older partners, partners with poor mental HRQoL, and dyads where the patient had low perceived control over the HF reported an increase in caregiver burden over time.
- The most burdensome areas related to caregiving were decreased personal freedom and not being able to cope with practical issues related to the HF.
- To feel supported in the care, dyads need long-term contacts and easy access to healthcare professionals with whom trustful relationships are built.
- Nurses need to be responsive to relational issues that sometimes arise between the dyads during the illness trajectory.

SVENSK SAMMANFATTNING

Hjärtsvikt är ett allvarligt kroniskt tillstånd som oftast kräver livslång behandling. Den medicinska behandlingen har förbättrats, vilket innebär att patienter med hjärtsvikt nu lever längre med sin diagnos, och vården sker mestadels i hemmet med stöd av patientens partner. Att ta hand om en sjuk närstående innebär en belastning för partnern, både när det gäller psykiskt och fysiskt välbefinnande och hälsorelaterad livskvalitete. Samhället förväntar sig att partnern ska vara den som ansvarar för en stor del av vården och omsorgen, men under de senaste åren har det utvecklats en större medvetenhet om partners betungande situation. Ett fåtal interventionsstudier har riktat sig gemensamt till par där en part är drabbad av hjärtsvikt men resultaten har dock inte givit en entydig vägledning om hur interventioner bör utformas för att förbättra utfallet för både patient och partner.

Avhandlingens övergripande syfte var att utvärdera långtidseffekten av en intervention med psykosocialt stöd och utbildning till patienter med hjärtsvikt och deras partners samt att utforska parens upplevda behov av stödjande omvårdnad.

Samtliga patienter och deras partners deltog i en randomiserad kontrollerad studie där både kontroll- och interventionsgrupp fick sedvanlig vård och interventionsgruppen deltog dessutom i en sjuksköterskeledd intervention med psykosocialt stöd och utbildning. I samtalen utgick sjuksköterskorna från en framtagna samtalsguide som var inspirerad av en hälsofrämjande modell. Målsättningen var att öka parens kunskap och deras upplevda kontroll över sjukdomen samt minska partners vårdgivarbörda. Totalt inkluderades 155 par, 71 par i interventionsgruppen och 84 par i kontrollgruppen.

I den första delstudien var syftet att utvärdera långtidseffekten av interventionen. Resultatet visade inga signifikanta skillnader mellan grupperna gällande sjukvårdskonsumtion, hälsorelaterad livskvalitet, depressiva symptom eller upplevd kontroll över sjukdomen.

Syftet i delstudie två var att undersöka utvecklingen av vårdgivarbörda och sjuklighet över tid hos partnern till den hjärtsviktssjuka. Resultatet visade inga signifikanta skillnader mellan interventionsgrupp och kontrollgrupp gällande någon dimension av vårdgivarbörda eller sjuklighet efter 24 månader, dock sågs en signifikant ökning av vårdgivarbördan över tid i båda grupperna. Störst vårdgivarbörda upplevde äldre partners, partners till patienter med låg grad av kontroll och partners som skattade låg mental hälsa.

I delstudie tre analyserades sjuksköterskornas dokumentation nedskriven under interventionen. Sjuksköterskorna skrev ner sammanfattningar av samtalen med paren, vad som diskuterats som svårigheter, glädjeämnen och överenskommelser. Detta gjordes för att se hur den hälsofrämjande modellen passade behoven hos par med hjärtsvikt och hur modellen använts under besöken. Modellen bestod av tre komponenter, en kognitiv, en stödjande och en beteendekomponent. Dessa tre delades i sin tur upp i vad som uppfattades vara hinder, parens resurser och upplevda självförmåga. Resultatet visade att modellen använts och uppfyllde parens behov.

I delstudie fyra var syftet att utforska de upplevda behoven av stödjande omvårdnad paren upplever, för att utveckla en förståelse för hur stödet bäst ska utformas. Åtta fokusgruppsintervjuer med par från både kontrollgruppen (n = 8) och interventionsgruppen (n = 11) genomfördes. Analysen bildade två teman; *Kontinuerlig vägledning hjälper paren genom sjukdomens olika faser* och *När bördan delas stöder paren*

varandra och andra. I det första temat beskrev paren ett behov av att få kunskap om hjärtsvikt för att kunna hantera vardagen. Regelbundna besök och tillgång till långsiktigt stöd i form av ett telefonnummer till sjukvårdspersonal, exempelvis hjärtsviktssjuksköterskan, som kände paren var viktigt, och om någon dessutom tog hand om och frågade om partners situation ökade parets trygghet. I det andra temat beskrev paren ett behov av att både patienten och partnern får vara närvarande vid sjukhusbesöken. Gemensamma besök möjliggjorde att båda fick samma information och möjlighet att ställa frågor. Att träffa andra par i samma situation och dela bördan vid gruppträffar skulle ge paren möjlighet att både få stöd och stödja andra.

Sammanfattningsvis visar denna avhandling att interventionen med psykosocialt stöd och utbildning till par av patienter med hjärtsvikt och deras partners inte påverkade sjukvårdskonsumtion, hälsorelaterad livskvalitet, symptom på depression, upplevd kontroll eller partners vårdgivarbörda. För att känna stöd i situationen behöver paren långsiktigt stöd och lättillgänglig tillgång till hälso- och sjukvårdspersonal där förtroendefulla relationer byggs. Den sammanfattande tolkningen av samtliga delstudier föreslår att konceptet Långsiktigt stöd läggs till hälsofrämjande modellen vid användning av modellen till patienter med hjärtsvikt och deras partners.

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