Linköping University Medical Dissertations No. 1181

Supportive care for patients with heart failure and their partners

- A descriptive and interventional study

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Linköping 2010

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Printed in Sweden by LiU-Tryck, Linköping, Sweden, 2010

ISBN 978 – 91 – 7393 – 406 - 0
ISSN 0345 – 0082

To my family

No one knows what he can achieve,
until he has tried

Publicus Cyrus

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ORIGINAL PAPERS I-V

ABSTRACT

Background: Having the support of a partner is essential for both health related quality of life and survival in heart failure patients. However, caring for a patient with heart failure may affect the health related quality of life, well-being and cause a burden for the partner. The partner is expected to be responsible for the care, which may have consequences for the heart failure patient's long-term health and well-being. Further research to determine health related quality of life, well-being, caregiver burden and needs of partners is warranted as well as studies evaluating interventions targeting patient-partner dyads.
Aim: The overall aim was to describe how the life situation of patient-partner dyads was influenced by heart failure and to determine the effects of an intervention of follow-up with education and psychosocial support for patient-partner dyads.
Design and methods: The thesis is based on three quantitative studies and one qualitative study. The first two studies were descriptive and included 135 dyads (patient-partner) (**I, II**) and the randomised intervention study included a total of 155 dyads (**IV**). The qualitative study had a grounded theory approach. Thirteen partners were interviewed and data analysed using constant comparative method (**III**).
Results: Caregiver burden was perceived as moderate in 30% of the partners and the rest experienced a low caregiver burden. The patients' physical component score of SF-36, partners' mental component score of SF-36 and perceived control explained 39% of the caregiver burden (**I**). Patients had lower health related quality of life compared to their partners in all dimensions except in the mental health domain of SF-36 and lower quality-adjusted life year weights compared to their partners. Mental health scores were lower in partners compared to age and gender-matched references. All other health related quality of life scores and the quality-adjusted life year weights were comparable between the partners and the reference group. Patients had more depressive symptoms than their partners. There was no difference in the level of perceived control or knowledge about chronic heart failure between patients and partners (**II**). During grounded theory analysis confirmation was identified as describing the core category of the partners' individual needs. The core category theoretically binds together three underlying subcategories: security, rest for mind and body, and inner

strength. Confirmation facilitated acceptance and improvement of mental and physical health among partners (**III**). At the three month follow-up the dyad-intervention had improved perceived control in patients, but not in the partners. There were no other significant differences in the control and intervention group with regard to the dyads' health related quality of life and symptoms of depression. There were also no differences in the patients' self-care behaviour and partners' experiences of caregiver burden (**IV**).
Conclusions and implications: Partners to patients with chronic heart failure are at risk of decreased mental well-being. One third of the partners experienced a moderate caregiver burden and was therefore at a higher risk of poor mental health and decreased perceived control. During short-term follow-up the intervention with education and psychosocial support to dyads (patient-partner) improved the level of perceived control in the chronic heart failure patient group. By identifying partners' needs for security, rest for mind and body, and inner strength, healthcare professionals can confirm these needs throughout the caring process, from the critical care period and throughout rehabilitation at home. Interventions targeting dyads have been limited in previous research. Partners need to be prepared regarding the disease process, the daily regimen, hopes for the future and responsible care providers. They also need to be confirmed because they are vital to the patients' recovery. Further, the effects of the intervention study should also include a long-term follow-up as well as an evaluation of the health-economic perspective including direct and indirect costs of care.

Keywords: heart failure, cardiac surgery, caregiver burden, intervention, health related quality of life, nursing

LIST OF PAPERS

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

I. Ågren S, Evangelista L, Strömberg A. Do partners of patients with heart failure experience caregiver burden? (Accepted for publication in the European Journal of Cardiovascular Nursing)

II. Ågren S, Evangelista L, Davidson T, Strömberg A. The influence of chronic heart failure in patient-partner dyads – a comparative study addressing issues of health related quality of life. (Submitted)

III. Ågren S, Hollman-Frisman G, Berg S, Svedjeholm R, Strömberg A. Addressing spouses unique needs after cardiac surgery when recovery is complicated by heart failure. *Heart Lung* (2009) 38(4):284-291.

IV. Ågren S, Evangelista L, Hjelm C, Strömberg A. Dyads affected by chronic heart failure – a randomised study evaluating effects of education and psychosocial support to patients and their partners. (Submitted)

ABBREVIATIONS

ACE	Angiotensin Converting Enzyme
BDI-II	Beck Depression Inventory-II
CAS	Control Attitude Scale
CBS	Caregiver Burden Scale
EHFscBS	European Heart Failure Self-Care Behaviour Scale
GT	Grounded Theory
HF	Heart Failure
HRQOL	Health Related Quality Of Life
NYHA	New York Heart Association Functional Classification
PHF	Postoperative Heart Failure
QALY	Quality Adjusted Life Year
QOL	Quality Of Life
RAND	Research and Development
SF-36	Short Form-36
WHO	World Health Organisation

INTRODUCTION

Heart failure (HF) is a complex condition caused by an underlying heart disease, often in combination with other chronic diseases which complicates the heart failure process and course of events. There is no general accepted definition of HF. It is often a chronic condition and not a disease where the heart is unable to provide the different organs with adequate circulation of blood due to an abnormality in the heart and changes in the hemodynamic, kidney-, nerve- and hormone system (Dickstein et al. 2008). The most common HF symptoms are breathlessness, oedema, and fatigue. Treatment of HF is complex and contains stringent lifestyle modifications and multi-drug regimens. Adherence to the treatment regimen is essential for clinical outcomes such as survival and health related quality of life and therefore places strong demands on patients (Van der Wal et al. 2005). Research indicates that those who have a network of supportive social relationships and especially a partner have more favourable outcomes in terms of better self-care management (Sayers et al. 2008) and survival (Rohrbaugh et al. 2006). However the caregiving role has a significant impact on the general health perception in HF partners (Luttik et al. 2009a). Patients with HF have debilitating symptoms associated with psychological stress which can burden both them and their caregiving partners (Karmolovich 1994). HF has several negative consequences for the partner (Mårtensson et al. 2001, Evangelista et al. 2002, Mårtensson et al. 2003). Caregiver characteristics have been shown to affect patient outcomes, for example the emotional well-being of the partner has been shown to be an independent predictor of emotional well-being among HF patients (Mårtensson et al. 2003). Interventions targeting dyads are limited in previous research concerning scope and number. Partners need to be prepared about the disease process, the daily regimen, hopes for the future and responsible care providers. Further research to determine health related quality of life, well-being, caregiver burden and partners’ needs are therefore warranted as well as studies evaluating interventions targeting patient-partner dyads.

BACKGROUND

Heart failure

Definitions, etiology and epidemiology

Many definitions of HF have been put forward over the last 50 years (Poole-Wilson 1997). HF is a syndrome containing the following features; symptoms of HF, typically shortness of breath at rest or during exertion and/or fatigue, signs of fluid retention such as pulmonary congestion or ankle swelling and objective evidence of an abnormality of the structure or function of the heart at rest. Asymptomatic structural or functional abnormalities of the heart are considered as precursors of symptomatic HF (McDonagh et al. 1997, Wang et al. 2003).

There are only a limited number of ways in which the function of the heart can be affected. The most common causes of functional deterioration of the heart are damage or loss of heart muscle, acute or chronic ischaemia, valve dysfunction, increased vascular resistance with hypertension, or the development of a tachyarrhythmia such as atrial fibrillation. Coronary heart disease is by far the most common cause of myocardial disease, being the initiating cause in more than 70% of patients with HF (McDonagh et al. 1997, Wang et al. 2003). Valve disease accounts for 10% and cardiomyopathies for another 10% (Elliot et al. 2008).

Th extended Europe represents countries with a population of >900 million, and there are up to 26 million patients with HF in those 51 countries included in the European Society of Cardiology. The prevalence of HF is between 2 and 3% and rises sharply at ~75 years of age to approximately 10-20 % at 80 years of age and above. In younger age groups HF is more common in men because the most common cause, coronary heart disease, occurs earlier in males. In the elderly, the prevalence is equal between the sexes (Dickstein et al. 2008). The mean age of patients with HF in developed countries is 75 years. HF is the cause of 5% of acute hospital admissions, utilises 10% of hospital beds, and accounts for ~2% of national expenditure on health, mostly due to the cost of hospital admissions (Stewart et al. 2002).

Symptoms

The most common symptoms of HF are shortness of breath, fatigue, exercise intolerance and peripheral oedema. To state the degree of functional status and symptoms in HF, the (New York Heart Association) NYHA Functional Classification has been developed. There are 4 different classes of function, see table 1 (AHA et al. 1994).

Table 1. NYHA Functional Classification

NYHA Class I	No limitation, ordinary physical exercise does not cause fatigue, dyspnoea or palpitations
NYHA Class II	Slight limitation in physical activity, comfortable at rest but ordinary activities result in fatigue, dyspnoea or palpitations
NYHA Class III	Marked limitation of physical activity, comfortable at rest but less than ordinary activities result in fatigue, dyspnoea or palpitations
NYHA Class IV	Unable to carry out any physical activity without discomfort. Symptoms of heart failure are present even at rest with increased discomfort during any physical activity

Pharmacological and surgical treatment

Treatment of HF aims to relieve symptoms, to maintain a euvolemic state (normal fluid level in the circulatory system), and to improve prognosis by delaying the progression of HF and reducing cardiovascular risk. Basic HF pharmacological treatment with strong scientific evidence includes diuretics, Angiotensin Converting Enzyme (ACE) inhibitors/angiotensinreceptor blockers, beta blockers, and aldosterone antagonists (Dickstein et al. 2008). There is a significant evidence–practice gap in the pharmacological treatment of HF; particularly the underuse of ACE inhibitors and beta blockers and aldosterone antagonists which have been shown to provide mortality benefit (Jackson et al. 2005).

Surgical therapy is warranted in cases where HF is caused by a surgically correctable condition such as valve disease or coronary artery disease. Surgery with left ventricular assist devices or heart transplantation is considered in severe cases of cardiomyopathy unresponsive to pharmacological treatment (Nicolini & Gherli 2009).

Morbidity and prognosis

HF is a leading cause of hospitalisation for elderly patients and prognosis is poor with half of the patients dying within 4 years after diagnosis (Dickstein et al. 2008). Pathophysiological aspects such as poor left ventricular function, co-morbidity as well as psychosocial factors such as symptoms of depression, neuroticism, self-efficacy, perceived social support, and the quality of a patient’s marital relationship appear to have prognostic significance for morbidity and mortality in HF (Dickstein et al. 2008, MacMahon & Lip 2002, Murberg et al. 2001a, Murberg & Bru 2001b, Rohrbaugh et al. 2004, Coyne et al. 2001). Marital quality has been found to predict survival during an 8-year follow-up period. A self-estimated good marriage including sufficient emotional support also led to less severe symptoms and better mental health in HF patients (Rohrbaugh et al. 2006).

Living with heart failure

Patient perspective

The psychological and social concerns depending on physical needs were predominant for people with HF after discharge from hospital (Davidson et al. 2008).

The situation can be improved if healthcare professionals take into account the patient's lived experiences. Accurate and ethical care is a prerequisite for patients if they are to trust and surrender to formal care as well as be active and responsible for their own health process (Nordgren et al. 2007).

Successful self-management of HF includes identification of all the factors (both positive and negative) that influence patient behaviour. Numerous factors (eg, comorbidities and concern for family members) affecting HF self-management served as barriers to goal attainment in some patients. Goals set by patients reflected their life experiences and exemplified challenges regarding HF self-management. Some themes reflected the complexity of their lives, whereas other themes demonstrated levels of knowledge and motivation. Mutual goal setting was helpful in understanding the patients' perspective and their receptivity to the process of adopting health-promoting behaviours (Meyerson et al. 2009).

Health related quality of life (HRQOL) is a multidimensional, subjective concept that is affected by a variety of factors. Patients with HF defined HRQOL as their ability to 1) perform desired physical and social activities to meet their and their partners needs; 2) maintain happiness; and 3) engage in fulfilling relationships with others. Patients perceived a variety of factors as positively or negatively affecting HRQOL: physical (symptoms and good or poor physical status), psychological (mood and positive or negative perspective), economic (financial status), social (social support and ability to take part in social activities), spiritual, and behavioural (self-care). Patients perceived that HF had a serious impact on HRQOL but often, patients' positive self-evaluation of HRQOL contradicted their own definition of HRQOL and the factors affecting it (Heo et al. 2009).

HF patients had lower levels of HRQOL compared with the healthy control group, especially in the physical domain such as physical function, role physical, general health and vitality (Ekman et al. 2002).

Some patients described emotional and somatic symptoms of depression. They experienced negative thinking and multiple stressors that worsened their depressive symptoms. Patients managed depressive symptoms by engaging in activities such as exercise and reading, and by using positive thinking, spirituality, and social support (Dekker et al. 2009).

Spiritual well-being focuses specifically on measuring psychosocial dimensions. HF patients who experience higher spiritual well-being also perceive greater control over their disease. HF patients who adjust to personal changes and who also connect with others may develop meaning and purpose in life (Vollman et al. 2009).

Symptoms of depression, the most common mood disturbance in persons with HF, range in prevalence from 13% to 77% depending on the method of diagnosis and the timing of assessment (Thomas et al. 2003, Vaccarino et al. 2001, Jiang et al. 2001). Among ambulatory patients with HF, the incidence and prevalence of symptoms of depression were found to be higher than in the general population (Westlake et al. 2005, Gottlieb et al. 2004, Rutledge et al. 2006). Both depression and depressive symptoms are independently associated with hospitalisation and mortality in persons with HF (Friedmann et al. 2006, Sherwood et al. 2007, Jiang et al. 2004, Jiang et al. 2007). Depressive symptoms predict worse health status, physical and social functioning, symptom burden, and HRQOL in outpatients with HF (Rumsfeld et al. 2003).

Older adults with HF report anxiety levels 60% higher than those without cardiac disease and 40% of all individuals suffering from HF experience major levels of anxiety (Moser et al. 2004, Smith et al. 2007). HF is associated with anxiety levels as high as or higher than those seen in cardiac patients without HF or in patients with cancer or lung disease (DeJong et al. 2004, Moser et al. 2004, Riedinger et al. 2002).

Partner perspective

Aldred et al. (2005) reported that elderly people with HF have similar needs to people with other terminal illnesses. HF affected all aspects of their lives and in particular, curtailed everyday activities. Patients were very concerned about the 'burden' their illness placed on their partner, although partners did not conceptualise the situation in this way. The socially isolating influence of the condition on both patient and partner was compounded by a lack of professional input, and confusion about the diagnosis. Concerns about the future were common and, although few participants reported having been explicitly told about their prognosis, many made realistic statements about their limited life expectancy (Aldred et al. 2005).

HRQOL in partners seems to be affected by caring for a HF patient and the possible burden of the caregiving partner. Support of a partner is essential for health in HF patients (Luttik et al. 2005).

Partners of HF patients experience several life changes as reflected in the main themes: changes in life, changes in relationship, coping, and support. Changes in relationship are related to difficulties in communication and sexuality. Partners support patients in their daily activities; they often change their own daily schedule and have to adjust joint activities. Regaining a new balance together is one of the challenges that dyads face when confronted with HF. Anxiety is an important theme especially in the acute phase that can interfere with adequate coping strategies. Although most partners seem to cope relatively well, the impact of HF on their lives is profound (Luttik et al. 2007a).

Both patients' and partners' depressive symptoms and anxiety influenced their own HRQOL. Patients and partners with more depressive symptoms experienced poorer HRQOL. Patients whose partners had more depressive symptoms were more likely to indicate their own HRQOL as being poorer. Anxiety has similar actor and partner effects as depressive symptoms on HRQOL (Chung et al. 2009a).

Partners reported moderately poor physical and emotional health related quality of life. Those with more depressive symptoms at baseline were more likely to report that their lives had changed for the worse at 4 months. The most difficult caregiving tasks were those dealing with patients' behaviour problems; the most negative outcome was having less time for activities with friends (Pressler et al. 2009).

Findings have been inconclusive regarding whether HF patients or their partners have the lowest HRQOL. Luttik et al. found that partners' HRQOL was lower of HF patients and indicates that the HRQOL of partners seems to be affected by caring for the HF patient (Luttik et al. 2005). Important variables influencing HRQOL are the partner's own mental health and the perceived physical health of both partners and HF patients (Luttik et al. 2007b). The physical and emotional components in HRQOL were moderately poor in HF partners (Pressler et al. 2009).

Mårtensson et al. (2003) found that patients experienced significantly more symptoms of depression and worse physical component in HRQOL than partners. However, there were no significant difference between patients and partners in the mental component of their HRQOL (Mårtensson et al. 2003).

HF partners who were offered more involvement in discharge planning had higher scores regarding satisfaction, feelings of preparedness and perception of care continuity and were more accepting of their caregiving role than partners who were not offered involvement in discharge planning. In the follow-up of this data, partners who reported more involvement in discharge planning also reported better health than those who had little or no involvement in discharge planning (Bull et al. 2000a, 2000b, 2000c). Social support to informal caregivers has consistently been found to predict better outcomes for informal caregivers (Miller et al. 2001, Haley et al. 1996). Partner personality factors such as neuroticism and mastery have also been shown to relate to partner outcomes (Bookwala & Schulz 1998, Hooker et al. 1994). When life is close to collapsing, it can be held together and continues to be meaningful, with the help of close and significant relationships (Johansson Sundler 2008).

Theories of families and dyads

The basic definition of dyads is the fundamental unit of interpersonal interaction. The central logic underlying the concept dyads is that dyad-pairs are somehow related; that is, they are somehow connected (e.g., husband and wife, supervisor and supervisee) (Kenny et al. 2006).

The literature describes interpersonal influence as the essence of close relationships (Huston 1983). If the behaviour of one person is of no consequence to another person, it could hardly be said that they have a relationship, much less a close one. The ability to influence a partner is important to the functioning of the relationship (Cook 2001).

Improving the quality of family relationships is an important clinical issue. Social relationships are a significant determinant of emotional and physical health (Rook et al. 2004), and family members are vital for achieving optimal outcomes for elderly with chronic health conditions (Grady et al. 2000, Naylor et al. 2004, Rook et al. 2004). Shared care provides a structure to expand the view of family care to include both members of a care dyad and account for positive and negative aspects in the relationship (Sebern 2005).

The goal of the social relations model is to identify the sources of variability in dyadic relationships. Each of the models (interaction model, main effects model and transactional model) is integrated into a single structural - equation model of one person's relationship to another (Cook 2001). According to the family version of the social relations model (Cook 1993, 1994, Kashy & Kenny 1990) person A's thoughts, feelings or behaviour in relation to person B will be a function of four factors; (1) person A's actor effect (2) person B's partner effect (3) the unique relationship of person A to person B (i.e., a relationship effect) and (4) a family effect. Actor effects reflect characteristics of a person that influence all of that person's relationships, a kind of cross situational consistency. Partner effects reflect consistency in the behaviour a person elicits from or affords others. Relationship effects indicate the unique adjustment one person makes to another. Family effect is a group effect. Family effects are a function of factors that connect family members (e.g., culture and family norms) (Cook 2001). The family health system proposes that the nursing perspective of family life should include family dynamics, strengths and concerns. The interactive processes in the family unit consist of family relationships, communication, nurturance, intimacy and social support. The nurses' role is to assist the family to implement needed adjustment and adaption, facilitating family symptom management, individual and family growth, family understanding and promotion or improvement in family health (Anderson 2000).

Shared goals and a shared commitment to professional practice provide the essential building blocks of the dyad relationship. The dyad structure presents an opportunity for healthcare professionals and social workers to integrate their strengths and skills in a collaborative patient-centered effort (Carr 2009).

Caregiving

Caregiver burden

Most studies show that informal caregiving is associated with increased levels of emotional distress (Pinquart & Sörensen 2003).
Several predictors of negative caregiving in HF partners have been found. Female partners had lower levels of emotional well-being (Evangelista et al. 2002, Walden et al. 2001). They also reported more difficulty in performing helping behaviours to HF patients (Karmolovich 1994).

In other illness populations, female partners have been found to be consistently more distressed (Yee & Schulz 2000, Lutzky & Knight 1994). A close relationship to the care recipient and being young are both associated with poorer mental health outcomes for caregivers. For example, young spousal caregivers have generally been found to report greater caregiving strain than non-spousal caregivers (Cantor 1983). In older adults, caregiving appraisal significantly explained strain and depressive symptomatology (Schwarz & Roberts 2000). Lower levels of perceived control were a risk for decreased emotional well-being (Dracup et al. 2004).

Symptoms in HF patients have not been consistently related to partners' well-being. This is in contrast with findings in other partner populations, e.g., Alzheimer's disease (Pinquart & Sörensen 2003) and stroke (Schulz et al. 1988). Rohrbaugh at al. (2002) found that NYHA class was not related to partner emotional distress (Rohrbaugh et al. 2002). Employed partners perceived higher well-being, suggesting the benefits of work to caregiving than unemployed partners of older HF patients (Saunders 2010).

Consequences of caregiving

Individuals with moderate to severe HF are often reliant on partners for assistance with instrumental activities of daily life (e.g., shopping, house keeping) and sometimes even activities of daily life (ADLs, e.g., bathing or dressing) (DeGeest et al. 2003). Partners caring for an individual with HF may also often have to endure and attend to a range of problems. The combination of these factors has the potential to severely impact upon individuals providing informal care for HF patients. The fact that partners have to perform caregiving tasks is also related to feelings of burden, especially when it concerns tasks regarding personal care such as assisting with washing and bathing and moving in and around the house (Luttik et al. 2007b).

Among partners, depressive symptoms and levels of perceived stress were low; informal social support and caregiving appraisal were high. The interaction of partner stress and symptoms of depression were significant predictors of risk for hospital readmission (Schwarz & Elman 2003).

Health related quality of life

There are many different definitions of quality of life (QOL). These definitions emphasise different aspects, such as general satisfaction with life, financial circumstances, physical, psychological and social health (Farquhar 1995, Anderson & Burckhardt 1999, Karlsson et al. 2000). Based on the World Health Organisation (WHO) definition of health, HRQOL consists of three components of physical, psychological and social well-being. Measurement of HRQOL can identify person-centered problems, and improve the understanding of a person's subjective experience of health. This is important when evaluating treatment and care and may promote communication between patients and healthcare providers (Anderson & Burckhardt 1999, Bosworth et al. 2000, Johansson et al. 2004).
Research on HRQOL can help to shed light on the individual's own perceptions of their situation and how it has changed (Guyatt 1993a). An examination of HRQOL that explores all these various dimensions offers useful insights into the level of those dimensions and how they have changed (Bosworth *et al.* 2000, Kiebzak *et al.* 2002). Health status, functional status, and HRQOL are three concepts often used interchangeably to refer to the same domain of health (Patrick & Bergner 1990). The health domain ranges from negatively valued aspects of life, including death, to the more positively valued aspects such as role function or happiness (Guyatt 1993a). HRQOL is a concept that tries to embrace the spirit of the WHO definition of health (including physical, emotional, and social well-being) (WHO, 1948) by including both personal health status and social well-being.

Measuring health related quality of life

There are two general approaches in the measurement of HRQOL, generic instruments and disease-specific instruments (Guyatt 1993b, McDowell & Newell 1996). Generic instruments are especially useful for surveys and allow broad comparisons between HF and other diseases, but they may be unresponsive to disease-specific conditions (Guyatt 1993b). When the purpose of a study is to aid decision makers on issues regarding resource allocation and priority setting, it is central that different studies and interventions can be compared. Therefore, a general measure called quality adjusted life year (QALY), that combines health status and time, is often used. QALYs are calculated by multiplying a QALY weight with life years. The QALY weight is

expressed as a number between 1 and 0, where 1 represents full health and 0 represents death. There are several methods applicable to estimate the QALY weight. QALYs are used increasingly as endpoints in health economy evaluations (Guytt 1993b, Bullpitt 1996, Drummond & McGuire 2001*).*
Disease-specific instruments are designed to be responsive to specific HF symptoms such as; dyspnoea, fatigue, weakness, sleepiness, oedema (Bennet et al. 2000) and other aspects of impaired HRQOL and are therefore often used in clinical trials (Guytt 1993b).

Self-care behaviour

Self-care is defined as a naturalistic decision making process that patients use in the choice of behaviours that maintain physiological stability (symptom monitoring and treatment adherence) and the response to symptoms when they occur (Riegel et al. 2004). The term naturalistic decision making is used to describe how people make decisions in real-world settings. Naturalistic decision makers' focus on process rather than outcomes, make decisions based on the situation, allow the context to influence their decision-making processes, and base practical decisions on the information available at the moment (Lipshitz et al. 2001).
Self-care management refers to decision making in response to signs and symptoms. With regards to HF, self-care management requires that patients recognise a change (for instance an increasing edema), evaluate the change, decide to take action, implement a treatment strategy (e.g., take an extra diuretic dose), and evaluate the response to the treatment implemented. Patients themselves, often supported by their families and caregivers, are responsible for the vast majority of HF care (self-care). Even those who are seen in the office at relatively frequent intervals or who are telephoned at home are required to engage actively in self-care. As self-care involves behaviours such as taking medications, monitoring and interpreting symptoms, keeping appointments, and contacting healthcare providers when needed, it is impossible for a community-dwelling patient to avoid self-care (Riegel et al. 2009).
Self-care management is an important part of successful HF treatment and can significantly impact on symptoms, functional capacity, well-being, morbidity, and prognosis (Jaarsma et al. 2003, Dickstein et al. 2008). Good adherence has been shown to decrease morbidity and mortality and improve well-being (Granger et al. 2005). However, only 20–60% of patients with HF adhere to

their prescribed pharmacological and non-pharmacologic treatment (Evangelista & Dracup 2000, van der Wal et al. 2005). Data from the Euro Heart Failure Survey demonstrate that a large proportion of patients either misunderstand or have problems recalling that they have received recommendations regarding self-care management such as instructions regarding medications or diet (Lainscak et al. 2007). It is recommended that healthcare professionals provide comprehensive HF education and counselling (Dickstein et al. 2008).

A strong relationship between healthcare professionals and patients as well as sufficient social support from an active social network has been shown to improve adherence to treatment. It is recommended that family members be invited to participate in education programmes and decisions regarding treatment and care (De Geest & Sabaté 2003). Resources that partners drew on were acceptance, self-care, availability of support and a feeling that caring is a shared responsibility with the patient (Gysels & Higginson 2009). Patients should have adequate knowledge of their medical treatment, especially regarding effects, side effects, and how the medication should be taken and titrated. This may be challenging in patients with cognitive dysfunction (Strömberg 2005). Patients should be aware that the beneficial effects of therapy may be delayed and not have unrealistic expectations regarding the initial response to treatment. It must be explained that side effects are often transient, and it might take months to up titrate and assess the full effects of a drug. Interventions to improve adherence are recommended and should be targeted by the healthcare provider (Dickstein et al. 2008).

One study that followed up patients for an additional year after the intervention in a family based approach to improve self-management and adherence in HF patients, ended by reporting a similar deterioration in HRQOL in randomised patients in both the intervention and control groups (Dunbar 2003). Thus, no definitive conclusion about the impact of self-care on HRQOL can be made (Riegel et al. 2009).

Education

In its broadest sense, education is any act or experience that has a formative impact on the mind, character or physical ability of an individual (UNESCO 2009). Patient education is practiced using a process of a need and motivation to learn. Goals are mutually set with the patient for the exact learning needs.

Frequent evaluation and follow-ups are necessary to determine if educational goals are being met (Redman 2006).

Heart failure education

Whether the process is called patient education or self-management education, there is a consensus that educational preparation is a central non pharmacological strategy for long-term management of HF (Colonna et al. 2003, D'Alto et al. 2003, ICSI 2009). Education before hospital discharge is an important element of the care and treatment of HF (JCAHO 2009, AHRQ 2009, NQF 2009). Educational topics cited by most guidelines include understanding the causes, signs, and symptoms of HF, diet, salt, and fluid restrictions, medical treatment, exercise recommendation, lifestyle changes such as daily weights, symptom monitoring and responding promptly to changes in signs and symptoms (ICSI 2009, Dickstein et al. 2008, Hunt et al. 2005). It is recommended that healthcare professionals provide comprehensive HF education and counselling (Dickstein et al. 2008).

Process of learning

To learn is to acquire knowledge or skill. Learning may also involve a change in attitude or behaviour. Adults can learn to solve complex problems (Säljö 1979, Rogers 2003). Assuming that patients are responsible for their health, engaging them in the care and treatment process is essential. According to a widely acknowledged principle, adult learning is optimal when the learner is ready to learn. Adults have a need to be self-directed, goal-oriented, and practical, and to understand the reason for learning something (Merriam & Caffarella 1999). Above all, they expect to be treated with respect (Edwardson 2007).

AIMS OF THE THESIS

The overall aim was to describe how the life situation of patient-partner dyads was influenced by HF and to determine the effects of an intervention of follow-up with education and psychosocial support for patient-partner dyads.

Specific aims of the thesis were:

- To describe the levels and identify independent predictors of caregiver burden in partners of patients with chronic HF during the early post-discharge phase (Study I).

- To describe and compare health related quality of life, quality-adjusted life year weights, symptoms of depression, perceived control and self-estimated knowledge in patients with chronic HF and their partners (Study II).

- To compare health related quality of life and quality-adjusted life year weights in the partners with an age- and gender matched reference group (Study II).

- To identify, describe and conceptualise the individual needs of spouses of patients with complications of HF after cardiac surgery (Study III).

- To evaluate the effects of an integrated dyad care programme with education and psychosocial support to patients with chronic HF and their partners during a post-discharge period of 3 months after acute deterioration of chronic HF (Study IV).

METHODS

Design

In this thesis descriptive and comparative cross-sectional design (study I, II), qualitative design using Grounded Theory (GT) method (study III) and an experimental randomised design (study IV) were used.
In the quantitative studies, variables of interest and their operational definitions were identified, an intervention designed and then relevant data from subjects collected and analysed for description and evaluation. In the qualitative study, data were collected from narrative descriptions and analysed. The qualitative and quantitative paradigms complemented each other and led to a richer and more in-depth description of the life situation of patient-partner dyads (Polit & Beck 2008).

The studies (I-IV) are described in an overview in table 2.

Table 2. Overview of the methods included in study I-IV.

	Study I	**Study II**	**Study III**	**Study IV**
Design	Descriptive, correlational, cross-sectional	Descriptive, cross-sectional	Qualitative	Randomised, controlled design
Participants	135 patient-partner dyads	135 patient-partner dyads 135 age- and gender matched references for the partner group	13 partners	155 patient-partner dyads
Inclusion criteria	Patient diagnosed with chronic HF, NYHA class II-IV and a partner cohabit in a marriage-like relationship	Patient diagnosed with chronic HF, NYHA class II-IV and a partner cohabit in a marriage-like relationship	Cohabit in a marriage-like relationship with a patient with complicating PHF Theoretical sampling	Patient diagnosed with chronic HF, NYHA class II-IV and a partner cohabit in a marriage-like relationship
Age, mean, SD	71±12 patients 69±12 partners	71±12 patients 69±12 partners 68±11 reference group	65±13 partners	Patients C:73±10 I:69±13 Partners C:72±12 I:68±14
Methods	Questionnaire: CBS, SF-36, BDI-II, CAS, RAND, CCI	Questionnaire: SF 36, QALY weights, BDI-II, CAS, RAND, CCI	Grounded Theory, interviews	Questionnaire: CBS, SF-36, BDI-II, CAS, EHFscBS, CCI
Analyses	Descriptive, Pearson's and Spearman correlation, Linear regression analyses	Descriptive, Student t-test, Chi square test, One way ANOVA	Constant comparative analyses	Descriptive, Pearson's and Spearman correlation, Student t-test, Chi squaretest

Setting and participants

Patients and partners study I, II and IV

All patients diagnosed with chronic HF that had recently been admitted to hospital for treatment due to deterioration of HF were screened weekly. They were treated at a university and a county hospital in the Southeast region of Sweden. In study I and II baseline data 2-3 weeks after hospital discharge was collected (Figure 1) and in study IV baseline and 3 months follow-up data were collected (Figure 2). The partners were living with the patient in the same household. In study I,II dyads were recruited between January 2005 and September 2008. In study IV some more patients were included due to extended inclusion period to December 2008.

In order to be included in the studies both the patient and their partner had to give consent. The dyads were initially informed verbally of the study through a telephone call or during a visit to the HF clinic. Potential dyads who were interested in taking part in the study were given additional written information. A questionnaire packet was sent out to the dyads who agreed to participate in the study 2-3 weeks after discharge from the hospital.

Partners study III

In study III partners to patients with postoperative heart failure (PHF) following cardiac surgery were included. These partners were contacted after the patients were found through computer registries at 2 university hospitals in southern Sweden performing approximately 800 and 1400 cardiac surgical procedures respectively annually. Each hospital is the sole provider of cardiac surgery in its catchment area of 1 million inhabitants. The dyads received a letter in which they were asked to participate and they were instructed to accept or decline by mail. If they accepted, they were contacted by a phone call to book an appointment for the interview. Twenty patients and their partners were asked about being interviewed in the context about the partners’ life situation following the patients’ cardiac surgery. Subsequently thirteen partners accepted. Data were collected from partners, 10 women and 3 men, from February 2005 to June 2007.

Reference group in study II

A population survey was conducted by Folkhälsovetenskapligt Centrum on behalf of Hälso-och Sjukvårdsnämnden in 2006. The questionnaire was sent to a sample of individuals in Östergötland, Sweden, aged between 18-84 years. The sample comprised 13 440 individuals and the response rate was 54 %. The questionnaire covered areas such as lifestyle, self-rated health and issues of socio-economic nature (Folkhälsovetenskapligt Centrum 2006). From this sample, we received a file of 2291 individuals of the same age span who lived with a partner. From this group, 135 age-and gender matched partners were selected by an independent researcher who was not involved in the project.

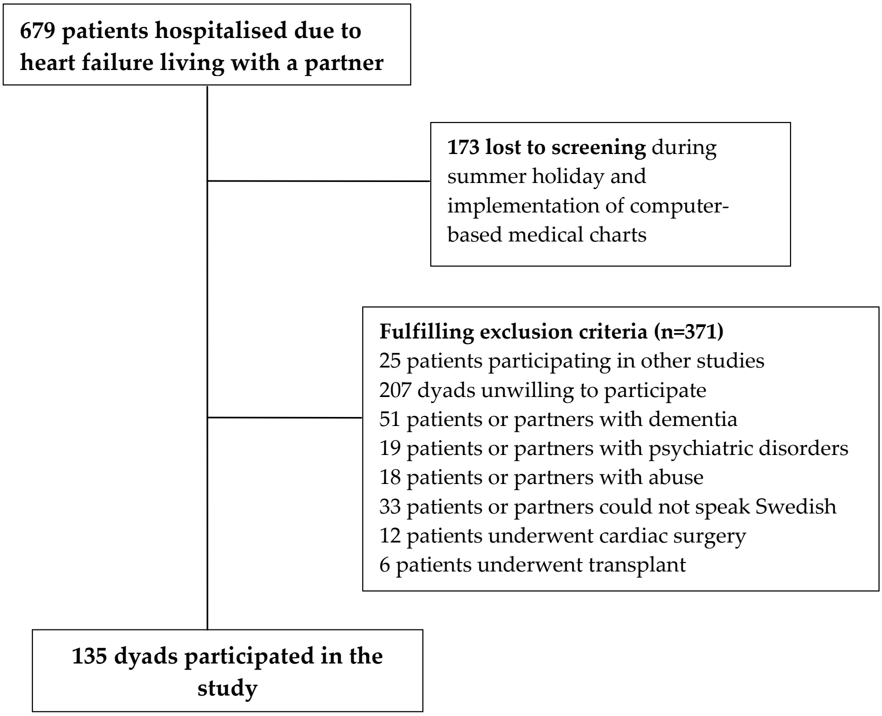

Figure 1. Flow chart illustrating the sample process in study I-II

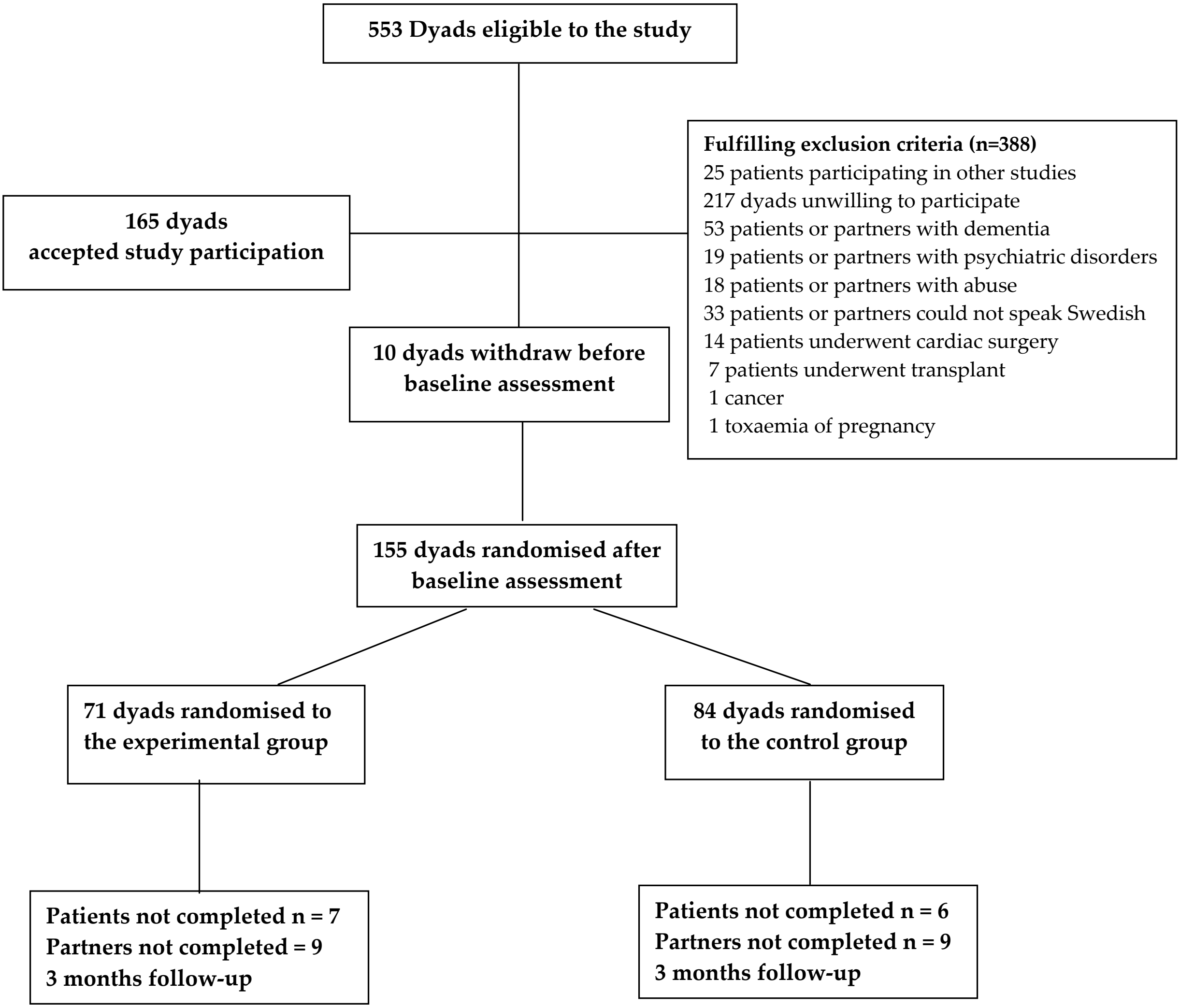

Figure 2. Flow chart illustrating the dyads through the clinical study.

Theoretical framework for the intervention

The intervention in the randomised study (IV) was based on a conceptual model developed by Stuifbergen et al. (1999). The concepts in Stuifbergen's model are rooted in Pender's model of health promotion (Pender et al. 1987) and Bandura's self-efficacy theory (Bandura 1997). The model assumes that barriers, resources, and self-efficacy help to determine whether or not an individual engages in health-promoting behaviours such as self-care. It is believed that people will participate in health-promoting behaviours if they develop knowledge and skills that address barriers and build resources and self-efficacy. The conceptual foundation of the study included a multidimensional definition of health and well-being, a holistic focus, and an emphasis on empowering patients with HF and their partners. Rather than focusing on the narrow clinical aspects of illness and disability, individuals are viewed as capable of achieving health and quality of life. Access to knowledge and resources are viewed as providing the basis for the choice of behaviours to sustain and enhance HRQOL (Stuifbergen et al. 1999). An integrated cognitive-behavioural framework that focused on problem solving, information acquisition, self-care management for symptoms, and emotional and social support for patient-partner dyads was used. The healthcare professional assists dyads in recognising and modifying factors that contribute to physical and emotional distress by changing thoughts and behaviours in a positive manner. Further to focus on solving problems to implementing strategies for self-care in HF. Computer-based education has been shown to be feasible and effective in terms of improving knowledge in elderly patients with HF and therefore a combined nurse-led and computer-based intervention has been tested and compared to conventional care in this study. See table 3.

Table 3: Content of each of the three modules utilised in the intervention

	Module 1	Module 2	Module 3
Cognitive Component	The circulatory system, definition of HF, medications and symptom management	Lifestyle modifications; diet, smoking cessation, alcohol, immunisation, regular exercise	Directing care, relationship and sexual activities, prognosis
Cognitive Outcomes	Increased knowledge of chronic HF syndrome and treatment	Increased knowledge of the rationale for lifestyle changes	Increased knowledge of chronic HF care and outcomes
Support Component	Introduce psychosocial support concept	Assess patient's need of support Modify caregiver behaviour	Asses partner's need of support Discuss partner's burden
Support Outcomes	Improved mental and physical functions	Strengthen self-care behaviour	Improved mutual support Decreased partner's 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 weight Monitoring of symptoms Flexible diuretic intake Adherence to medications	Salt and fluid restriction Influenza and Pneumococcal Immunisations Regular Exercise	Identifying life priorities and planning for the future
Teaching material	Booklet 1 – basic level, CD-ROM Flip chart	Booklet 2 – advanced level CD - ROM	Booklet 2 – advanced level CD-ROM

The Quantitative studies (Study I, II and IV)

Data collection and analysis

The questionnaires were sent by mail and the dyads completed them in their home. They included approximately 150 items in total at baseline and 100 items at the 3 month follow-up. The questionnaire package had the same order for every participant.
Demographic data of HF patients and partners were collected by questionnaire. Clinical data of the HF patients were collected by chart review.

Instruments

Caregiver burden scale

The Caregiver Burden Scale (CBS) is a 22-item scale that assesses subjectively experienced burden by caregivers to chronically disabled persons. The caregiver is asked to tick one of four boxes (not at all, seldom, sometimes, often) in order to score 1 to 4 for each question. The total burden index is the mean of all items and higher scores indicate greater burden. The overall mean caregiver burden score was divided into three groups: low burden (1.00–1.99), medium burden (2.00–2.99) and high burden (3.00–4.00). The instrument comprises five factors: general strain, isolation, disappointment, emotional involvement and environment. A mean value is calculated for each factor including: General strain: 8 items. Isolation: 3 items. Disappointment: 5 items. Emotional involvement: 3 items. Environment: 3 items. Factors measured the caregiver’s health, feeling of psychological well-being, relations, social network, physical workload and environmental aspects. A previous study on reliability showed high internal consistency for the five factors with Cronbach’s alpha values between 0.70 and 0.87, except for the factor environment, 0.53. A Swedish reproducibility study showed kappa values between 0.89 and 1.00, except for the factor environment which varied from 0.53 to 1.00 (Elmståhl et al. 1996, Andrén & Elmståhl 2005, 2008).

SF-36

The SF-36 (Short Form-36) health survey is a scientifically tested instrument to measure self-reported physical and mental health. It is used to measure effects of well-being and functional ability. The health survey can be generally used and is widely distributed internationally. SF-36 includes the feature well-being, often summarised in the concept of health related quality of life (Ware 2000).

The SF-36 is a short-form health survey consisting of 36 questions. It contains an eight-scale profile of scores as well as a summary of physical and mental measures. The SF-36 is a generic measure of health status as opposed to one that targets a specific age, disease, or treatment group. The SF-36 has proven useful in comparing general and specific populations, estimating the relative burden of different diseases, differentiating the health benefits produced by a wide range of different treatments, and screening individual patients (Manocchia et al. 1998). The SF-36 was constructed to satisfy minimum psychometric standards necessary for group comparisons. The eight health concepts measured in the SF-36 were selected from dozens included in the Medical Outcomes Study (Stewart & Ware 1992) and represent the most frequently measured concepts in widely-used health surveys that have been shown to be affected by disease and treatment (Ware et al. 1993, Ware 1995). SF-36 items also represent multiple operational definitions of health, including function and dysfunction, distress and well-being, objective reports and subjective ratings, as well as both favourable and unfavourable self-evaluations of general health status (Ware et al. 1993). Eight dimensions are weighed together in two consecutive indexes; physical component score and mental component score. The physical part is made up of the dimensions of physical functioning, physical role functioning, bodily pain and general health. The mental part of the four dimensions is made up of vitality, social functioning, emotional role functioning and mental health. The scores are transformed into values of 0-100, with a higher score indicating a better health related quality of life (Ware et al. 1993, Ware & Sherbourne 1992). SF-36 is a well established and frequently used instrument and has been found to have good reliability and validity (Sullivan et al. 1995, Ware & Sherbourne 1992, Ware 2000). Most reliability estimates exceeded the .80 level (Sullivan et al. 1995).

Beck depression inventory-II

The Beck Depression Inventory-II (BDI-II) (Beck et al. 1996a) is used to measure depressive symptoms, which are characterised by feelings, thoughts, and behaviours that reflect sadness, loss of interest in life, and negative perceptions of self or future. The BDI-II is a self-report instrument consisting of 21 items rated on a 0–3 scale indicating feelings over the past 2 weeks, where higher scores indicate more severe depressive symptoms (Beck et al. 1996a). The instrument remains widely used in research (Richter et al. 1998). Symptoms of depression can be defined as having two components: the affective component (e.g. mood) and the physical or somatic component (e.g. loss of appetite). The cut-off scores used are: 0–13: no symptoms of depression; 14–19: mild symptoms of depression; 20–28: moderate symptoms of depression; and 29–63: severe symptoms of depression (Beck et al. 1996a). The BDI-II has been found to have good validity and high internal consistency (α=.91) (Beck et al. 1996b).

Control attitude scale

Patients' perceptions of control over their cardiac illness were measured by the Control Attitudes Scale (CAS) (Moser & Dracup 1995). The CAS consists of four belief statements measuring perceptions of personal and family control in the context of cardiac disease. It 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 individuals' own perception of situational control and their perception of the degree to which a family member perceives situational control. Items related to a family member's perception of situational control are included in the CAS because of the theoretical assertion that the patient's and family's perceptions of situational control are mutually influential (Moser & Dracup 1995). Patients respond to the items by indicating their feelings about their condition on a 7-point scale from 1 (not at all) to 7 (very much). The total score range is 4 to 28 with higher scores indicating stronger perceptions of control over the illness (Moser et al. 2007). The CAS is a reliable (inter-item correlations) and sensitive tool with regards to cardiac patients (Moser & Dracup 1995, Moser et al. 2007, Dracup et al. 2003, Gallagher et al. 2003). Shapiro et al. (1996) concluded that there is an increasing agreement among clinicians and researchers that control beliefs are important when determining general health and well-being. For example, higher perceptions of control are related to positive outcomes such as improved self-esteem, purpose in life, quality of life, and positive mood (Shapiro et al. 1996). Investigators have examined perceived control in a variety of clinical populations (e.g., cancer, mental illness, rheumatoid arthritis, diabetes, myocardial infarction, and HF) and have shown that higher perceptions of control are associated with better psychosocial adjustment (e.g., less anxiety, symptoms of depression, emotional distress and improved self-esteem) to both acute and chronic stressors, including chronic illness (Doerfler et al. 2005, Dracup et al. 2004, Hasson-Ohayon et al. 2006, Manne & Glassman 2000, Taylor et al. 1991, van der Wal 1993). Increased perceived control was associated with positive psychosocial outcomes among individuals living with chronic illnesses such as HF. Reliability and validity testing across studies revealed Cronbach's alpha values for the CAS ranging from .77 to .89 (Moser & Dracup 1995). A psychometric testing for the Swedish translation has shown good validity and a reliability coefficient alpha >0.80 for the patient version and between 0.60 and 0.70.for the partner version (Franzén et al 2010).

Knowledge questionnaire (RAND)

Knowledge Research and Development (RAND) is an instrument that contains items about the patients' and their partners' understanding of HF, how medicines work and the prevention of HF. The remaining part of the questionnaire deals with substantial items regarding what a HF patient should do in different situations and what is typical for these patients. It includes 21 items and in this study we analysed the first three separately and the rest to a total knowledge score where a correct answer scored one and a wrong answer scored zero. Crohnbach's alpha was 0.83 in a study of cardiac patients from the US (Caldwell et al. 2005, Simons-Morton et al. 1998). There were some problems related to homogeneity in the Swedish translation of the items in RAND. Several of the items had a poor correlation with the total sum. Further validation of the Swedish version of RAND is ongoing. Results from RAND in this thesis have therefore been interpreted with caution in study I and II and excluded from study IV.

European self-care behaviour scale (EHFscBS)

This scale is a 12-item self-administered questionnaire with a Likert-scale ranging from 1 (I completely agree) to 5 (I completely disagree) as scoring format (range 12 to 60). The scale addresses several items concerning self-care behaviour of patients, for example daily weighing, fluid restriction, exercising or contacting a healthcare provider. After being tested and validated in 442 patients from two centres in Sweden, three in the Netherlands and one in Italy, the scale has been translated into several languages. Reliability and validity have been tested and the internal consistency reliability measured by Cronbach's alfa was 0.81 (Jaarsma et al. 2003). The scale has been further reliability tested and validated with an internal consistency of 0.77. A nine-item version was further evaluated with a Crohnbach's alpha of 0.80 (Jaarsma et al. 2009).

Charlson co-morbidity index scale (CCI)

The co-morbidity index is a validated method of classifying co-morbidity to predict short-and long-term mortality from medical records as well as health care costs. Participants are asked to indicate whether or not they have a history of medical problems in 12 areas (e.g. heart disease including HF, cancer, stroke, renal disease) with responses of yes or no. It replaces direct measures of the severity of an illness that require a prospective data collection. The Charlson index assigns weights for a number of major conditions present among secondary diagnosis. The index score is the total of assigned weights and represents a measure of the burden of co-morbid disease. Illness severity can be divided into: Not ill, mildly ill, moderately ill and severely ill. Inter-rater and test-retest reliability was good, ranging from 0.74-0.95 (Charlson et al. 1987).

Statistical analyses

Descriptive statistics were carried out in all study variables such as numbers, percentages, mean and standard deviations. For group comparisons in clinical and socio-demographics characteristics chi square, student t-test or ANOVA were used. All statistics used in study I, II, IV were dependent on data level and distribution.

Missing data was low (0.7 – 8.1 %) in all instruments. Missing data on SF-36 were imputed by the mean of the subscale if only one item in a subscale was missing; otherwise missing items were not replaced. Missing data of other instruments was not replaced. Cronbach α coefficients were calculated for all scales to evaluate internal consistency reliability. Cronbach α was > 0.7 for all scales except Knowledge Questionnaire_RAND and CAS-family version in the Swedish translation.

Statistical analyses were performed using SPSS version 15.0. In study I linear regression analyses were used. The dependent variable caregiver burden was entered in three steps. The independent variables gender, age, symptoms of depression, health related quality of life, perceived control, knowledge, co-morbidity and NYHA class were first entered separately into univariate analyses with the dependent variable. In the next step the variables were grouped into three groups (characteristics, physical and mental) depending on the variable type. Characteristics included variables on age, gender, number of morbidities in patients and partners measured by CCI, patient-partner knowledge on heart failure measured by RAND and patient-partner perceived control measured by CAS. Physical included variables on the physical components of SF in patients and partners and NYHA classification in patients. Mental included variables on depressive symptoms in patients and partners measured by BDI-II and the mental components of SF in patients and partners. The variables which were significantly predictive of caregiver burden based on univariate analyses entered the stepwise forward regression within each group. Those variables with a p-value < 0.1 associated with caregiver burden were included to identify the combination of the variables with the most predictive power. The significance level was set at $p \leq 0.05$ with reduced p-values in post hoc analyses.

For the analysis of socio-demographic and clinical characteristics χ^2 test and ANOVA statistics between patient, partner and reference group was used. Student's t-test and χ^2 test were used for group comparisons depending of the distribution and data level. One-way ANOVA models with post-hoc analysis (Tukey) were used when comparing HRQOL and QALY weights in patients, partners and the reference group. Factorial ANOVA was used to determine the interaction effect for group (patient, partner and reference group) and gender in HRQOL, QALY weights, perceived control, symptoms of depression and knowledge.

In study IV a randomisation was used to secure equal distribution of potentially confounding characteristics between the intervention and control group. The effects were analysed by categorising and mean difference in all variables of interest between baseline and 3 months by using χ^2 test or student t-test.

The majority of the tests used in study I, II and IV were parametric. It is usually not a problem since e.g. t-test is such a robust test if the sample size is sufficient and the data come from a Gaussian population (Motulsky 2010). The reason for using parametric tests was to have the possibility to do comparisions with results from other previous studies, but also the possibility of doing regression analysis. When there was a sum score in the instrument parametric tests were used. χ^2 test was used if the scale was classified in categories.

The qualitative study (Study III)

Grounded Theory

In order to provide a deep understanding of the meaning of the partners' needs from a social context, GT method was considered to be suitable.

GT has its theoretical foundations in symbolic interactionism. A symbolic interactionistic approach assumes that the organisation of social life arises within the society itself from the process of interaction between members of the society. Symbolic interactionism aims to understand the symbolic meaning of how people manage situations through interpretive communication. The focus is on small-scale interaction rather than large-scale settings (Blumer 1969).
The development of GT was influenced by symbolic interactionism, which facilitates the understanding of the adaptation of how people manage social processes (Glaser & Strauss 1967). An adaptation process could be possible through communication, to understand the environment and create a social reality that provides meaning to the people involved. Symbolic interactionism and GT focus on the meaning of different central experiences to people and is firstly pointed out to oneself and secondly interpreted into action. Thirdly, the symbolic world could be understood by others through interaction (Blumer 1969, Mead 1967).

Analysis

In this study the goal was to discover the partners' meaning of their needs in their social context and how they continuously try to manage their life situation (Glaser & Strauss 1967). The data collection was carried out through interviews. Interviews allow the flexibility to ask the respondent to clarify issues essential to the understanding of the partners' needs. An interview guide with three guiding questions, in accordance with the study aim, was used (Glaser 1998).

The participants were selected based on differences such as age, gender, education level, time since surgery and distance to the thoracic centre. Data were collected and analysed through constant comparative analysis to generate categories and properties for generating a core category. This process was ongoing until theoretical data saturation was reached. When data saturation was achieved, that is, when no further information was added, a deeper and systematic analysis of the data was performed (Glaser 1978).

The interviews were tape recorded and transcribed verbatim. The data and written data from field notes were read through several times and an open coding was made line by line in the margin. Through analyses line by line with an open mind, substantive codes were generated that is a conceptualising on the first level of the abstraction process. Theoretical memos were used as written records about substantive codes and their theoretically coded relationships (Glaser 1998). The substantive codes were compared with previous data and similarities and differences occurred while categories emerged. The theoretical sampling and the analyses using constant comparison went on simultaneously until data saturation was reached (Glaser 1998). Data were examined several times to ensure the relevance and verify their fit. The categories were related to each other and a core category emerged. During data analyses the categories and the core category were discussed, modified and constantly refitted to represent, fit and work in order to explain the data about the partners' needs (Glaser 1998).

Trustworthiness was ensured through strict adherence to the systematic methods of GT in data collection and analysis (Lincoln & Guba 1985). Through constant comparison of the data the findings adequately express and fit the data that they purport to conceptualise (Glaser 1998, Schreiber & Stern 2001). Workability was ensured as the core category was meaningful, relevant and in accordance with the aim of the study and the categories explained the partners' needs. The data were grounded empirically to further secure fit and workability. Objectivity and relevance of the data were ensured by agreement between three independent researchers analysing the data to each other and thereafter by two external researchers who verified the results. Relevance of the results in the present study is important in order to give the core category and the categories transferability to other partners in similar situations (Glaser 1998, Glaser 1978).

Ethical aspects

The studies presented in this thesis were performed in accordance with the Helsinki declaration. Studies I, II, III and IV were approved by the Regional Ethical Review Board (Dnr M03-568 and M178-04).

The patients and partners in studies I, II and IV were contacted and given verbal information about the study, the procedures, the confidential nature of the study and that withdrawal from the study would not affect their future care. The patients and partners that chose to participate gave written informed consent before entering the study. In study III the patients and partners received a letter where they were asked to give written informed consent before being contacted and were given verbal information about the study.

RESULTS

Caregiver burden in partners (I)

This study describes levels of caregiver burden and identifies independent predictors of caregiver burden in partners of patients with chronic HF. The partners were significantly younger than the patients (69 ± 12 years vs 71 ± 12 years; $p<0.0001$) and the majority of partners were females (75%).
The majority of partners (68%) reported a low level of caregiver burden. However, one third of the partners reported a moderate caregiver burden. A decreased patients’ physical component score of SF-36 ($p< 0.001$), decreased partners’ mental component score of SF-36 ($p< 0.001$) and lower perceived control ($p<0.01$) accounted for 39% of the variance in the multivariate model of the total level of caregiver burden. See table 4. The dimension with the highest value was general strain dealing with the lack of personal freedom, followed by isolation involving limited social interaction and disappointment comprising of loneliness, physical burden, financial impact and the feeling that life was unfair. See table 5.

Table 4. Results of the final stepwise model of predictors of caregiver burden.

	Beta	**t**	**P-value**
Partners’ mental health index	-0.38	-4.74	0.001
Patients’ physical health index	-0.31	-4.25	0.001
Partners’ perceived control	-0.21	-2.59	0.01

Dependent Variable: total caregiver burden, adjusted R^2 0.39

Table 5. Result of the subscales of Caregiver Burden Scale (n=134).

	Mean	*SD*	*Minimum*	*Maximum*
Total	1.77	0.54	1.00	3.32
General strain	1.88	0.64	1.00	3.75
Isolation	1.80	0.77	1.00	4.00
Disappointment	1.72	0.63	1.00	3.80
Emotional involvement	1.66	0.63	1.00	4.00
Environment	1.63	0.56	1.00	3.00

Health related quality of life in patient-partner dyads (II)

This study describes and compares HRQOL, QALY weights, symptoms of depression, perceived control and self-estimated knowledge in patients with chronic HF and their partners. It also compares HRQOL and QALY weights between the partners and an age- and gender-matched reference group. The partners and the reference group did not differ significantly in co-morbidity when compared with the disease groups. However, the patients showed significantly more co-morbidity than the partners (p<0.001) when compared with the disease groups and 52 % of the patients were in NYHA class III. The partners experienced a similar level of HRQOL as the reference group except in the mental dimension where partners scored significantly worse (p<0.001). There were no differences in the mental dimension between partners and patients but the remaining dimensions in HRQOL were significantly lower in patients (p<0.001). See figure 3.

In QALY weights the patients also scored significantly lower than the partners. The partners and the reference group did not differ in QALY.
When analysing the individual items in the BDI-II the partners had the most impact on changes in sleep patterns, loss of appetite and sexual interest. Patients reported increased symptoms such as loss of energy, changes in sleep patterns, fatigue or exhaustion and loss of sexual interest. There was a significant difference with regard to depressive symptoms between the patients and partners (<0.001). The partners scored lower levels of depressive symptoms than the patients with 2 % reporting moderate level in symptoms of depression compared to 14 % of the patients.
In perceived control over the heart disease no significant differences between partners and patients were found. Similar results were found in the level of knowledge on HF issues without significant differences between partners and patients. However, the patients' self-estimated understanding of HF, the pharmacological treatment and prevention of HF was higher compared to the self-estimation of the partners.

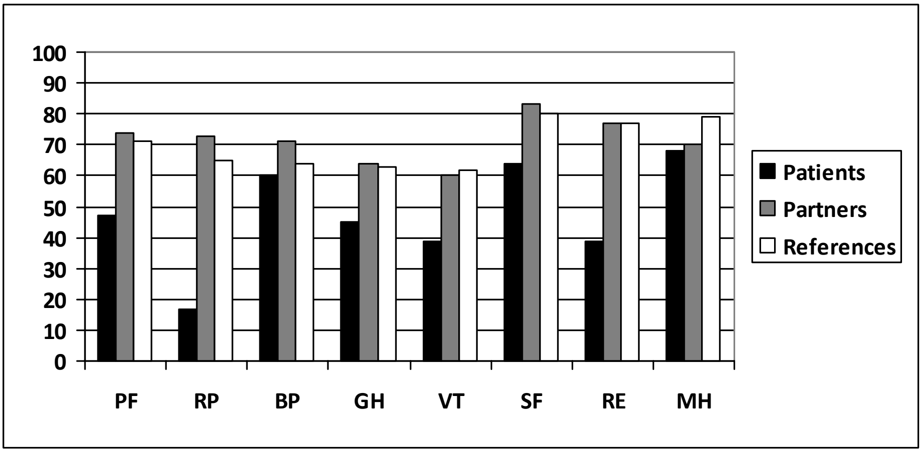

Figure 3. Health related quality of life in the eight dimensions of SF-36 in patients with chronic HF, their partners and the partners' age- and gender-matched reference group.

PF= Physical Functioning, RP= Role-physical, BP= Bodily Pain, GH= General Health, VT= Vitality, SF= Social Functioning, RE= Role-emotional, MH= Mental Health.

Partners’ needs after cardiac surgery complicated by heart failure (III)

The focus of this GT study was to identify, describe, and conceptualise the individual needs of 13 partners of patients having PHF following cardiac surgery. During analysis the core category Confirmation and three underlying categories emerged describing the partners’ individual needs: security, rest for mind and body, and inner strength.

For the partners it was most important to be confirmed by the healthcare professionals in a supportive environment and throughout the entire rehabilitation process. They needed a positive attitude, a mutual and respectful relationship to gain inner strength and to adapt to the situation. It would facilitate daily life if partners received assistance when the patient returned home.

Security included honesty and straightforward information, to have the possibility to contact healthcare professionals at the intensive care unit and to receive confirmation whenever needed. To be received with understanding, respect, and kindness, and to be informed correctly and given hope, lead to partners' enhanced confidence and feeling of being involved in the patients' care. Partners felt secure when healthcare professionals had a positive attitude, were spontaneous, positive, and pleasant, had a true commitment, and seemed to enjoy their work.

Partners needed rest for mind and body to gain inner strength, to feel better and to forget the difficult situation for a moment. They wished to be in a peaceful, relaxing environment without disturbance and the possibility to stay overnight. It was an advantage for the partners to document feelings and experiences. Afterwards, those patients and partners needed to reflect on the rehabilitation process. Another important aspect was the possibility to do relaxing activities such as gardening, inviting friends over, talking about something else, and taking a bicycle ride or a walk.

The partners were surprised by their unexpected inner strength and power in the difficult situation. They needed following counselling and psychosocial support to understand their reactions and anxiety but also to reflect on the situation. The partners’ limitations to answer the patients’ questions depended on the lack of memories of the acute phase. It was important to guide the partners in an empathic and individual contact on how to manage the situation at home and communicate with healthcare professionals.

Confirmation happens when the partners' individual needs for support are fulfilled. Support from healthcare professionals and a social network is needed to achieve security, to rest the mind and body, and to promote inner strength.

Evaluating effects of education and psychosocial support to patient-partner dyads (IV)

To evaluate effects of education and psychosocial support, a randomised controlled intervention study with 155 dyads was carried out. After 3 months the intervention group had a significantly higher level of perceived control over the heart disease (p<0.05) in patients. The partners' perceived control remained unchanged see table 7.
No differences were found between the intervention and control groups for the dyads regarding HRQOL and symptoms of depression. Neither the partners' caregiver burden nor patients' self-care differed between the groups after 3 months.

Table 7. Perceived control in patients and partners measured by the Control Attitude Scale.

diff 0-3 months		**N**	**Mean**	**Std. Deviation**	**p-value**
Patients Perceived control	Control	76	-0.43	4.8	0.03
	intervention	64	-2.2	4.5	
Partners Perceived control	Control	75	-1.8	10.0	0.60
	intervention	62	-1.0	4.7	

DISCUSSION

Discussion of Results

Patients with HF and their partners face many challenges associated with the heart disease. High levels of social support in a close relationship have been found to improve HRQOL (Chung et al 2009b), self-care management (Sayers et al. 2008) and survival (Rohrbaugh et al. 2006) in patients with HF. However, being a partner and caring for a patient with HF may have negative effects on the partner's HRQOL. The main focus in previous research has been on describing and improving patient outcomes. Further studies were needed to explore the dyads' and partners' role, situation and needs. This thesis therefore highlights different aspects of the patient-partner dyads self-perceived life situation in relation to chronic HF. The results describe the impact of chronic HF on the partners' experienced caregiver burden and HRQOL, the needs of the partners during deterioration and complications of PHF and the effects of an intervention including education and psychosocial support to patient-partner dyads.

To our knowledge, no previous study has compared HRQOL and QALY weights of partners of patients with chronic HF with both the patients and an age- and gender matched reference group. Previous studies have found lower levels of HRQOL in patients with HF compared with healthy controls (Ekman et al. 2002, Lesman-Leegte et al 2009). Further, lower HRQOL and more depressive symptoms in patients compared to partners have been confirmed in previous studies (Evangelista et al. 2002, Mårtensson et al. 2003, Pihl et al. 2005, Luttik et al. 2009b). The partners in our study experienced a HRQOL equal to an age- and gender-matched reference group and better than the patients. However, the mental dimension was similar to the patients and significantly worse than the reference group (Study II). Pihl et al. (2005) also found that patients and partners had an equal level of depressive symptoms, while we found significantly less depressive symptoms among the partners (Study II).

Chung et al. (2009a) found that partners' depressive symptoms and anxiety negatively impacted patients' HRQOL, with high levels of depressive symptoms or anxiety in the partner predicting poorer HRQOL in the patient. In contrast, they found that neither patients' depressive symptoms nor anxiety predicted their partners' HRQOL (Chung et al. 2009a). Other researchers who have compared HRQOL of partners and patients with other chronic illnesses reported that patients with vasculitis had lower HRQOL in all dimensions compared to their partners (Carpenter et al. 2009). Similar to our findings stroke patients had lower HRQOL in all dimensions except the mental-emotional compared to their partners (Jönsson et al. 2005).

In our study, we also wanted to capture the dyads' QALY weight of their health state and also compare the partners with their references. We found that the QALY weight of the partners were equal to the reference group, while the patients had significantly lower QALY weights than the partners (Study II).

Being a chronic HF patient may decrease HRQOL and chronic HF also affected the partners, but not to the same extent. We found that the majority of the partners experienced a low level of caregiver burden. However, it is important to note that almost one third of the partners experienced moderate levels of caregiver burden. General strain, defined as loss of personal freedom, was the subscale where the partners felt most burdened. Pressler et al. (2009) also found that partners experienced limitations in their daily life and personal freedom when using their resources to help their loved one who suffered from HF. Healthcare professionals should be aware of the fact that partners who perceive moderate levels of caregiver burden are at risk for falling ill themselves and for an untimely death (Schulz & Beach 1999). It should be considered that the partners' mental health was impaired in comparison with a reference group (Study II). The partners' mental health and perceived control but also the patients' physical health explained 39 % of caregiver burden (study I). In addition Saunders (2009) found that caregiver burden and HRQOL had a strong correlation. In a study with 50 partners of HF patients' caregiver burden explained 62% of caregiver HRQOL and caregiver depressive symptoms explained an additional 2% of the variance in HRQOL (Saunders 2009).

Confirmation is the core component for fulfilling the partners' individual needs for support during deterioration and complications of PHF. Support from healthcare professionals and a social network are needed to achieve security, to rest the mind and body, and to promote inner strength (Study III). In study III partners were in a situation where they needed to interact with healthcare professionals and with their social network. Their purpose was to

care for the patient and felt no resentment at the situation. The partners' main concern was to be confirmed and feel safe. Their solution was rest for mind and body and their own strength. The essence of inner strength is defined as a central human resource that promotes well-being (Roux et al. 2003). The interaction between members is a process regarding human groups in the society exists in action (Blumer 1969). According to the Poulschock-Deimling model the partner's feelings and distress arose both from the patient's behavior and difficulties with social functioning. Burden consequences consisted of the impact of caregiving on the partner's interpersonal relationships with the patient and others in the family and social restriction (Montgomery et al. 1985).
Study III was planned to be a starting point for an intervention study directed toward patient-partner dyads with complications of PHF following cardiac surgery. This is an ongoing randomised study and the results will be presented in the coming years to come. A part of the PHF partners' situation is similar to that of partners of chronic HF patients. The differences between PHF partners and chronic HF partners are probably small. The results in Study III are in agreement with the way the intervention in Study IV was designed and conducted. The intervention of chronic HF patient-partner dyads was also inspired by previous research on chronic HF management programmes (Strömberg et al. 2003), theories of social relation models and family health systems (Cook 2001, Anderson 2000). The patients' thoughts, feelings or behaviour in relation to the partner will be a result of different factors. The patient and partner are individuals with their own characteristics. They affect each other in a unique relationship. The nursing perspective focuses on the relation within the patient- partner dyad and the dynamic strengths and concerns. It is important to understand how the dyads' relationship, communication, nurturance, intimacy and social support work and how the partners' burden is influenced by the patients' HF (Cook 2001). The nursing perspective in this situation is to guide the dyad in adjustment and adaption through advice and support to facilitate symptom management, individual and dyad growth, dyad understanding and promotion or improvement in dyad health (Anderson 2000).

When we evaluated the effects of education and psychosocial support to dyads, the patients' perceived control had increased significantly after 3 months in the intervention group. Despite this improvement in perceived control, self-care behaviour remained unchanged in the intervention group.

Sucessful self-care management require that the patients have both tactical skills ("how to") and situational skills ("what to do when") (Dickson & Riegel 2009). In some patients these skills evolve over time and with practice (Riegel et al. 2007). Most patients, however, need assistance to master self-care skills (Riegel et al. 2009). Although education that increases knowledge and understanding of HF is essential (van der Wal et al. 2006, Cline et al. 1999), knowledge is not sufficient, and self-care is sometimes unrelated to knowledge (Durose et al. 2004). Self-care requires active decision making and concerted behaviour change (Riegel et al. 2009).

Evidence for the beneficial impact of social support on outcomes of cardiovascular disease and HF is growing, along with evidence that social isolation and living alone are associated with poor self-care. Unmarried or unpartnered HF patients report greater symptoms of depression (Havranek et al. 2004), and are at risk of poor self-care, whereas those in partnered relationships exhibit lower levels of emotional problems over time (Riegel et al. 2009). In our sample there were 14 % of detected symptoms of depression in chronic HF patients. The intervention did not decrease symptoms of depression or improve HRQOL during short-term follow-up. However, only data from the short-term follow-up have been presented in this thesis and further effects of the intervention might be found after a longer period of follow-up. Hence, it was unexpected that the dyad intervention, focusing on education and psychosocial support, did not improve any partner outcomes and no other patient outcomes apart from perceived control. Future interventions may need to have an extended focus on the partners' health and well-being in order to improve partner outcomes.

Discharge planning and follow-up after hospitalisation are often insufficient, leading to poor self-care behaviour, inadequate support for the patients, and suboptimal treatment. Poor or non-adherence to medication, diet, or symptom recognition is common (Evangelista & Dracup 2000, van der Wal et al. 2005) and may be responsible for over one third of hospital readmissions. Management programmes are designed to improve outcomes through structured follow-up with patient education, optimisation of medical treatment, psychosocial support, and access to care (Dickstein et al. 2008).

A cross sectional design was employed recruiting 75 HF dyads. Older patients who perceived their health as better reported better shared care communication. Partner dyads perceived more reciprocity in their relationship than non-partner dyads (Sebern & Riegel 2009). This study supports the important role that partners play in the care of HF patients. The emotional well-being of partners was an independent predictor of patient well-being

(Evangelista 2002). Chronic HF affected the partners' mental function and one third experienced a moderate caregiver burden. Therefore evaluating caregiver burden in relation to chronic HF is of clinical relevance in order to find partners in need of more support from the healthcare system in order to avoid suffering, deteriorating health and untimely deaths. Confirmation facilitated acceptance and improvement of mental and physical health among partners. The results of this thesis cause reflections on the reasons for the partners' absence of improvement after the intervention. This type of intervention has previously been tested on patients and may have limitations when addressed to partners. An addition to the dyad intervention for partners could be for them to meet other partners in the same situation and jointly discuss their situation (e.g. support groups). The intervention should maybe also include other health care professionals (physiotherapist, social worker etc) that have a different focus on the dyads health than nurse.

Methodological considerations

The studies in this thesis had mainly a quantitative design although one had a qualitative design. Together the research approaches completed each other in different perspectives. The advantage of a quantitative approach is the possibility to measure the reactions of a great number of people, carry out comparisons and statistical analysis of the data. This gives a broad and generalisable set of findings. By contrast, qualitative methods produce detailed information about a much smaller number of people. This increases the depth of understanding of the people and situations studied, but generalisability is limited (Patton 2000).

A weakness of the cross-sectional studies was that the life situation for the dyads was only measured once and cross-sectional design is limited in finding causal conclusions. However, it does not suffer from many of the difficulties that affect other designs, such as recall bias and loss of follow-up (Altman 1991). The strength of the first study was the analysis of the caregiver burden in relation to the other independent variables in three steps.

Continued research should focus on analysing the patient-partner dyads HRQOL in relation to perceived control and depression. Patients (actors) and partners might influence each others mental health and perceived control. This could be analysed according to the Actor-Partner Interdependence Model using regression. The patient and partner predictor variables are regressed on patient and partner outcome variables in a single regression model. Actor effect is the impact of a person's emotional distress on his/her own HRQOL. Partner effect is the impact of a person's emotional distress on his/her partner's HRQOL (Chung et al. 2009a).

The second study was strengthened by comparing the partners' HRQOL with an age-and gender-matched reference group. Reference groups provide the norm and contrast needed for comparison and evaluation of group and personal characteristics which people refer to when evaluating their own qualities, circumstances, attitudes, values and behaviours. The first two baseline studies included 135 dyads and the intervention study included 20 extra dyads. Random allocation gave all the subjects the same chance of receiving either treatment and was to prevent bias (Altman 1991). Although an increased inclusion time the sample was limited to 155 dyads. An assumption of the sample size regarding rehospitalisation/death was done before the randomised intervention study. The analysis in study IV presents no such data as it is a short-term follow-up, but power was assumed on perceived control and was based on a level of .05, 80% power and leading to a need for a sample size of 90 participants. A larger sample size leads to increased precision in estimates of various properties of the population and the power of the study detects an effect of a specified size (Altman 1991). It was difficult to include patient-partner dyads as more than 60% of the chronic HF patients did not have a partner. Patients and partners were also unwilling to participate due to old age, fatigue or illness.

The questionnaires for the baseline assessment were sent to the dyads after they had confirmed participation in the study. However, after consenting 10 dyads withdraw from the study before completing baseline assessment and being randomised. At 3 month follow-up 18 partners and 13 patients were lost to follow-up, one of the 13 patients had died. The patients were more willing to fill in the questionnaires than partners, the internal missing data were 0.7-8.1 % at baseline and at 3 months up to 10.9 % following a reminder. The higher percentages were the partners' missing value, despite the fact that the study was intended for the dyads. A plausible explanation is the tradition in healthcare which is directed primarily to patients and secondly to partners. A limitation in our study is that we did not collect demographic characteristics from dyads who declined to participate because our missing values were low. The primary aim when looking at non-participants is to try to investigate if these persons exhibit some central characteristics and if it influences negatively on the representative of the outcomes (Altman 1991).

The majority of the partner group was females in all four studies of the thesis. This gender distribution was also seen in a large study by Luttik et al. (2009b).

However, when controlling for gender and group differences no differences were found.

In contrast to the other studies, the partners in the qualitative study were targeted to patients with PHF following cardiac surgery. Previous studies have described the partners' life situation for up to 6 months through both cross sectional and qualitative approaches. These partners were interviewed up to 18 months following cardiac surgery. It was interesting to increase our knowledge of how partners adapt their experience and understand how to guide the patient after cardiac surgery through their life situation. To manage their situation they also needed a healthcare professional to guide them when their life situation seemed too difficult. Most of the theoretical perspectives examined thus far focus on a particular aspect of human experience. Their theoretical frameworks direct us to particular aspects of human experience as especially deserving of attention in our attempt to make sense of the social world. In contrast, GT focuses on the process of generating theory rather than a particular theoretical content (Patton 2002). Glaser believes that the method will result in a theory that describes what actually happens in humans (Glaser & Strauss 1967).

Quantitative research uses several criteria to assess the quality of a study and two of the most important criteria are reliability and validity. Reliability refers to the consistency of the measurement. The instrument measures the same way each time under the same condition with the same subjects. For testing of our instruments, the items should achieve consistency. Validity concerns whether the results are cogent, convincing and well grounded. It is important to use valid instruments where symptoms of depression and nothing else were measured. Another aspect of validity concerns our intervention. Did the intervention bring about improvements in the dyads' outcomes or were other factors responsible for their progress? Was there a consistency with our results and theory? (Polit & Beck 2008).

In qualitative research, the researcher is the instrument. The credibility of the GT study depends more on the skill, competence and rigor of the researcher's fieldwork. Trustwothiness was ensured through strict adherence in included sample and following the analysis process. To achieve trustworthiness, GT method emerged categories which explained the partners' needs. These findings should represent this group (Patton 2002).

Clinical implications

- Caregiver burden was especially affected in the dimension of general strain in partners to patients with chronic HF. General strain includes the experienced lack of personal freedom. A deteriorated mental health could also be seen in the partners. The dyads should be given special attention when experiencing a high burden, low perceived control, and poor mental and physical health. Interventions to increase personal freedom are warranted.

- As a consequence of the heart disease healthcare professionals should be aware of the risk of impaired emotional well-being in partners of patients with chronic HF and acknowledge their specific needs.

- Partners of patients with PHF need to be confirmed to feel security, rest for mind and body and inner strength. It is important with strategies to facilitate the partners’ recovery in the rehabilitation process.

- By identifying partners' needs healthcare professionals can confirm these needs throughout the caring process. Interventions to confirm partners' needs are important as they are vital to the patients' recovery.

- Healthcare professionals should assist the patient-partner dyads in changing factors that contribute to physical and emotional distress by changing thoughts and behaviour in a positive manner and assist the dyads in resolving problems related to chronic HF.

- There is a need to include the partners in a follow-up programme to strengthen the dyads’ situation. A partner-centred approach to educating and supporting patients with chronic HF and their partners is essential to ensure an adequate life situation for the dyads and improve patient outcomes.

Research implications

- A deeper understanding of the partners' experiences in relation to chronic HF patients is possibly further explored through a qualitative design. Focus groups or individual interviews could be an option.

- A greater knowledge of the vital link between partners' support and patient health outcomes with a clarification of the dynamic interaction that involves the dyad as the unit of analysis.

- Health-economic evaluation of cost-effective interventions and rehospitalisation/death is needed.

- Randomised intervention studies evaluating whether confirmation improves the partners' outcomes during patient recovery from PHF.

- Interventions to reduce caregiver burden should focus on providing the patient-partner dyads with strategies for improving health, self-care and coping by means of professional support. Interventions including exercise training, education and psychosocial support for the dyads need to be further evaluated.

- Further, to understand the entire care process, it is important to investigate healthcare professionals' perceptions of the partners' situation.

CONCLUSIONS

- Caregiver burden was experienced as moderate in 30% of the partners to chronic HF patients. The most burdensome areas in relation to caregiving were decreased personal freedom and limited social interaction.

- Caregiver burden was lower when the mental health of the partner was better, the physical health of the patient was better and when the partner experienced higher control over the cardiovascular-related health of the patient. Poorer mental health and lower perceived control in partners and poorer physical health in patients explained 39 % of caregiver burden.

- Lower mental health was found in partners to chronic HF patients in comparison with an age and gender-matched reference group, but the other dimensions of HRQOL were equivalent. Patients' HRQOL was in turn lower compared to the partners except in the mental dimension. QALY weights and depressive symptoms were also more influenced in patients than in partners.

- Partners to patients with PHF needed to be confirmed in order to achieve security, inner strength and rest for mind and body.

- Perceived control over the heart disease was significantly improved in chronic HF patients 3 months after an integrated dyad care programme with education and psychosocial support to patients and their partners.

SAMMANFATTNING PÅ SVENSKA (SUMMARY IN SWEDISH)

Det övergripande syftet med denna avhandling var att beskriva hur olika aspekter av livssituationen för patienten med kronisk hjärtsvikt och dennes partner påverkades av hjärtsvikten. Syftet var också att fastställa effekterna av en intervention med uppföljning av utbildning och psykosocialt stöd för patienter med kronisk hjärtsvikt och deras partner 3 månader efter utskrivning efter en akut försämring av kronisk hjärtsvikt.

Stöd från en partner har stor betydelse för välbefinnandet och den långsiktiga hälsan för patienter med hjärtsvikt. Att vårda en patient med hjärtsvikt kan påverka den hälsorelaterade livskvaliteten och välbefinnandet negativt och orsaka en börda av att vårda för partnern. Samhället förväntar sig att partnern ska vara den som ansvarar för mycket av vården och omsorgen. Tidigare forskning har visat att de som har ett nätverk av stödjande sociala relationer och framför allt en partner bedriver mer framgångsrik egenvård och har bättre överlevnad. Partner till patienter med hjärtsvikt som erbjöds att delta vid utskrivningsplaneringen hade en högre tillfredställelse, kände sig mer förberedda, upplevde bättre vårdkontinuitet och accepterade sin vårdgivarroll mer än partners som inte erbjöds deltagande i utskrivningsplaneringen. Partners som rapporterade ett större engagemang i utskrivningsplanen rapporterade också en bättre hälsa än de som hade liten eller ingen inblandning i planeringen. Det är motiverat att undersöka om livskvalitet, välbefinnande, vårdgivarbörda och partners behov kan påverkas samt utvärdera insatser riktade på patient och partner som en enhet.

I avhandlingen studerades patienter med kronisk hjärtsvikt som varit inlagda för akut försämring och deras partners. Partners jämfördes även med en ålders- och könmatchad referensgrupp. Vi studerade även partners till patienter med hjärtsviktkomplikationer efter hjärtoperation. Patienterna och deras partners tillfrågades om deltagande och fick i två av studierna svara på frågeformulär. I en annan studie blev partners intervjuade. I den avslutande studien jämfördes två grupper av patienter och partners. Den ena gruppen fick sedvanlig vård medan den andra gruppen lottades till att även få utbildning och psykosocialt stöd för att hantera livssituationen och bedriva egenvård för kronisk hjärtsvikt.

I den första delstudien studerades vilka faktorer som var relaterade till upplevd vårdgivarbörda när patienten försämrades i sin hjärtsvikt. Ökad vårdgivarbörda hade ett samband med att patientens fysiska hälsa försämrades, partners mentala hälsa var dålig och den upplevda kontrollen över hjärtsjukdomen var låg. Vårdgivarbördan upplevdes som måttlig hos 30% av partners. Det var minskad personlig frihet och minskade sociala kontakter som upplevdes som mest betungade.

Syftet i delstudie två var att jämföra hälsorelaterad livskvalitet, kvalitetsjusterade levnadsår, depressiva symtom, upplevd kontroll över hjärtsjukdomen och kunskap hos patienter med kronisk hjärtsvikt och deras partners. Vi jämförde även hälsorelaterad livskvalitet och kvalitetsjusterade levnadsår hos partners med en ålders- och könmatchad referensgrupp. Patienterna hade lägre hälsorelaterad livskvalitet jämfört med deras partners utom i mental hälsa och lägre kvalitetsjusterade levnadsår i förhållande till sina partners. Mental hälsa var lägre hos partners i jämförelse med en referensgrupp. I övrigt var det ingen skillnad mellan partners och en referensgrupp i hälsorelaterad livskvalitet och kvalitetsjusterade levnadsår. Patienterna hade mer depressiva symtom än sin partner. Det var ingen skillnad i upplevd kontroll över hjärtsjukdomen eller kunskap i kronisk hjärtsvikt mellan patienter och partner.

I delstudie tre intervjuades partners till patienter med hjärtsviktskomplikationer efter hjärtoperation. Det gjordes för att identifiera deras individuella behov. Bekräftelse i kombination med trygghet, vila för kropp och själ och inre styrka underlättade för partners att acceptera situationen och förbättrade den mentala och fysiska hälsan.

Den sista delstudiens syfte var att utvärdera effekterna av utbildning och psykosocialt stöd till patienter med kronisk hjärtsvikt och deras partners. Efter 3 månader hade den upplevda kontrollen förbättrats hos patienter, men inte hos partners. Det fanns inga andra skillnader mellan kontroll och interventionsgruppen med avseende på hälsorelaterade livskvalitet och depressiva symtom. Det fanns heller inga skillnader i egenvårds beteende hos patienter och partners upplevda vårdgivarbörda.

Sammanfattningsvis visar denna avhandling att partners till patienter med kronisk hjärtsvikt löper risk för nedsatt psykiskt välbefinnande. En tredjedel av de partners som upplevde en måttlig vårdgivarbörda, hade därför en högre risk för sämre mental hälsa och minskad upplevd kontroll. Efter en kort uppföljningstid med insatser av utbildning och psykosocialt stöd till patient och partner gavs en förbättrad upplevd kontroll hos patienter med kronisk hjärtsvikt men inte hos deras partners.

Genom att identifiera partners behov av trygghet, vila för kropp och själ och inre styrka kan hälso- och sjukvårdpersonalen bekräfta deras behov efter hjärtoperation. Insatser som är inriktade på patienter och partners har varit begränsad i tidigare forskning. Partners måste vara förberedda för att kunna hantera sjukdomsprocessen, de dagliga behoven, förhoppningar inför framtiden och vårdgivaransvaret. De måste också bekräftas eftersom de är avgörande för patienternas tillfrisknande. Långtidseffekterna av utbildning och psykosocialt stöd bör även utvärderas utifrån patienters och partners perspektiv och med avseende på det hälsoekonomiska perspektivet inklusive direkta och indirekta kostnader för vård.

ACKNOWLEDGEMENTS

I want to express my gratitude to everyone who supported me throughout my thesis that would otherwise never become a reality. I would especially like to thank:

All patients with chronic heart failure and their partners. Thank you for being available for participate in the studies. Without your participation in questionnaires, interviews and in the intervention, this thesis had not been possible.

Anna Strömberg, Professor, my excellent supervisor. Thank you for guiding me in the research process through support, knowledge, skill, wisdom and constructive criticism. You have inspired me to reach my goals with enthusiasm and always tried to give me time. Thank you also for your friendship.

Rolf Svedjeholm, Professor, my skilled co-supervisor. Thank you for your interest, curiosity, sense of humour, being available and supporting me with research expertise in thoracic surgery.

Sören Berg, PhD, my enthusiastic co-supervisor. Thank you for your positive, engaged, great interest for nurses' research to improve nursing care for patients, partners and for being available.

Gunilla Hollman Frisman, Lorraine Evangelista, Thomas Davidson, Kristofer Årestedt, my co-authors and collaborators in the project. Thank you for valuable and competent knowledge but also for good friendship.

Anna-Christina Ek, professor emeritus, **Sussanne Börjeson**, associate professor and assistant head of department, **PhD students**, **senior lecturers** at the **Division of Nursing Science**. Thank you for important and interesting discussions during seminars and wonderful friendship.

Carina Hjelm, Helen Nyberg and Anette Brostedt, thank you for invaluable contribution to the intervention and for your friendship.

Annette Waldemar, Lillevi Nestor, Heart failure clinic, Vrinnevi hospital, Norrköping. Thank you for your contribution in the intervention.

Kristina Olsson, Stefan Franzén, Erik Håkansson and all co-workers at the Department of Cardiothoracic Surgery. Thank you for giving me the confidence to do research and for your interest in my research process.

Bitte Wallin, Susanne Hellberg Karlsson, thank you for your contribution when I chose to begin with research.

Lotta Björk, Lisa Johansson, Maj Britt Tornell, Mikaela Lindholm, Helen Karlsson, Heart Centre; **Yvonne Roshagen**, Heart Lung Division, Lund, **secretary** of Emergency clinic, **Cecilia Hedenstierna**. Thank you for valuable achievements of my data.

The Swedish Institute for Health Sciences, Lund, **Inga Lill Rahm Hallberg, Sölve Elmståhl, Synneve Dahlin Ivanoff, Anna Karin Edberg, Edith Andersson**, **PhD students**. Thank you for the opportunity to be a PhD student at workshops with regular educational opportunities and support in my research process.

Anna Enblom, Mathilda Björk, Marie Cederfeldt, Harshida Patel, thank you for invaluable friendship during workshops at the Swedish Institute for Health Sciences.

Erika Lindén, Sofia McGarvey, thank you for the support and administrative activities during my PhD student time.

Karl Wahlin, thank you for good guidance on statistical advice.

Library staff, Faculty of Health Sciences, thank you for always being there when I needed literature.

My friends, thank you for a great friendship and support before and during my PhD student time.

My parents, thank you for your love and incredible support all my life.

My family, thank you for always being available.

My husband, **Lennart** and our sons, **Jonathan, Simon and Josef**. Thank you, without you, no life.

Thank you!

The studies of this thesis were financially supported by grants from the **Linköping University**, **Swedish Research Council**, **Swedish Institute for Health Sciences, Heart and Lung Foundation, Heart and Lung Disease National Association, Lions Research Foundation.**

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