The Couples’ Experiences of Patients’
Physical Limitation in Daily Life Activities and
Effects of Physical Exercise in Primary Care when
having Chronic Heart Failure

Emma Pihl
To my family

“Education is for improving the lives of others and for leaving your community and world better than you found it“

Marian Wright Edelman
Abstract
The aim of this thesis was to explore and describe couples' experiences of patients' physical limitation in activities of daily life and evaluate the effects of an exercise programme in primary care when having chronic heart failure (CHF).

In Study I, a comparison between patients with CHF and their spouses was made regarding health-related quality of life and depression. In the thesis a comparison was also made between patients, spouses and specific age and gender matched norms. There were statistically significant differences in health-related quality of life between patients and spouses as well as between patients and their norms as in SF-36 scores. The deteriorated health-related quality of life in patients was most present in the physical component but also in social function in the mental component. There were no differences between patients and spouses in depression symptoms.

In Study II, patients with CHF described their conceptions of physical limitation in daily life activities. A phenomenographic approach made it possible to identify variations of the conceptions and the referential aspects that emerged were: need of finding practical solutions in daily life, having realistic expectations about the future, not believing in one's own ability and losing one's social role in daily life.

In Study III, spouses' conceptions about the physical limitation in daily life activities in a loved one with CHF and the impact these limitations had on their daily life were examined. The phenomenographic approach resulted in different referential aspects. These were: losing self-containment, missing communality, accommodating to the situation and finding satisfaction in life.

Study IV aimed at determining effects of an exercise programme in primary care in elderly patients with CHF. The intervention period was 12 months with continuous exercise in the primary care centre and in the patients' homes. Tests of physical capacity showed significant consistent improvement in the exercise group in arms and shoulders during the intervention and in the 6 minute walk test at 3 months compared to the control group. The physical dimension of Minnesota living with heart failure was significantly improved at 3 months and Euroqol5D-VAS was significantly improved at 3 and 12 months in the exercise group compared to the control group. The thesis shows that patients and spouses conceive a variety of issues of physical limitation in daily life and the physical component of health-related quality of life is the most affected. The physical capacity in patients is possible to affect with an exercise programme in primary care and patient homes. The exercise programme is beneficial in terms of physical capacity in the upper body and walked distance in 6 minutes.
Abstract

The aim of this thesis was to explore and describe couples’ experiences of patients’ physical limitation in activities of daily life and evaluate the effects of an exercise programme in primary care when having chronic heart failure (CHF). In Study I, a comparison between patients with CHF and their spouses was made regarding health-related quality of life and depression. In the thesis a comparison was also made between patients, spouses and specific age and gender matched norms. There were statistically significant differences in health-related quality of life between patients and spouses as well as between patients and their norms as in SF-36 scores. The deteriorated health-related quality of life in patients was most present in the physical component but also in social function in the mental component. There were no differences between patients and spouses in depression symptoms. In Study II, patients with CHF described their conceptions of physical limitation in daily life activities. A phenomenographic approach made it possible to identify variations of the conceptions and the referential aspects that emerged were: need of finding practical solutions in daily life, having realistic expectations about the future, not believing in one’s own ability and losing one’s social role in daily life. In Study III, spouses’ conceptions about the physical limitation in daily life activities in a loved one with CHF and the impact these limitations had on their daily life were examined. The phenomenographic approach resulted in different referential aspects. These were: losing self-containment, missing communality, accommodating to the situation and finding satisfaction in life. Study IV aimed at determining effects of an exercise programme in primary care in elderly patients with CHF. The intervention period was 12 months with continuous exercise in the primary care centre and in the patients’ homes. Tests of physical capacity showed significant consistent improvement in the exercise group in arms and shoulders during the intervention and in the 6 minute walk test at 3 months compared to the control group. The physical dimension of Minnesota living with heart failure was significantly improved at 3 months and Euroqol5D-VAS was significantly improved at 3 and 12 months in the exercise group compared to the control group. The thesis shows that patients and spouses conceive a variety of issues of physical limitation in daily life and the physical component of health-related quality of life is the most affected. The physical capacity in patients is possible to affect with an exercise programme in primary care and patient homes. The exercise programme is beneficial in terms of physical capacity in the upper body and walked distance in 6 minutes.
Original papers

The thesis is based on following papers, referred to by Roman numerals:

Paper I


Paper II

Pihl E, Fridlund B, Mårtensson J. Patients’ experiences of physical limitations in daily life activities when suffering from chronic heart failure; a phenomenographic analysis. Scandinavian Journal of Caring Sciences 2010; e-published.

Paper III

Pihl E, Fridlund B, Mårtensson J. Spouses’ experiences of impact on daily life regarding physical limitations in the loved one with heart failure; a phenomenographic analysis. Canadian Journal of Cardiovascular Nursing 2010;20:9-17.

Paper IV

Pihl E, Cider Å, Strömberg A, Fridlund B, Mårtensson J. Exercise in elderly patients with chronic heart failure in primary care; effects on physical capacity and health-related quality of life. European Journal of Cardiovascular Nursing; Submitted.

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### Abbreviations

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<tr>
<td>CHF</td>
<td>Chronic heart failure</td>
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<tr>
<td>DRI</td>
<td>Disability rating index</td>
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<tr>
<td>EQ5D-VAS</td>
<td>Euroqol-5D, visual analogue scale</td>
</tr>
<tr>
<td>HADS</td>
<td>Hospital anxiety and depression scale</td>
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<tr>
<td>MLHFQ</td>
<td>Minnesota living with heart failure questionnaire</td>
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<tr>
<td>PSFS</td>
<td>Patient specific functional scale</td>
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<tr>
<td>SDS</td>
<td>Zung self rating depression scale</td>
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<td>SF-36</td>
<td>Short-form 36</td>
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<tr>
<td>6MWT</td>
<td>Six-minute walk test</td>
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<tr>
<td>RPE</td>
<td>Rate of perceived exertion</td>
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Background

**Chronic heart failure**

Definition, epidemiology and aetiology

Heart failure is a complex syndrome in the patient and includes the following features: symptoms of heart failure, typically shortness of breath at rest or during exertion and/or fatigue and/or ankle swelling, signs of fluid retention such as pulmonary congestion, and objective evidence of an abnormality of the structure or function of the heart at rest, Figure 1. Despite the aetiology of CHF it is a pump function injury and the functional deterioration of the heart is mostly due to damage or loss of heart muscle, acute or chronic ischemia, increased vascular resistance with hypertension or the development of tachyarrhythmia such as atrial fibrillation (Dickstein et al. 2008). Coronary heart disease is the most common cause of myocardial disease, being the initiating cause in ~70% of patients with CHF (Fox et al. 2001). Cardiomyopathies accounts for another 10% as well as valve disease accounting for 10%, but also endocrine and nutritional reasons exist (Dickstein et al. 2008). The prevalence of CHF is increasing, partly due to the ageing of the population, the success in prolonging survival in patients suffering from coronary events, and the success in postponing coronary events by effective prevention in those at high-risk or those who have already survived a first event (Senni et al. 1999, Murdoch et al. 1998). Further, efficient medical treatment in CHF is probably a contributor to improvements in the prognosis (Andersson et al. 2005). The prevalence of CHF is between 2 and 3 percent in the population. However, it rises sharply at ~75 years of age where also the mean age lies in developed countries. The prevalence in 70- to 80-year-old people is considered to be between 10 and 20% (Dickstein et al. 2008). CHF carries a worse prognosis than many common malignancies such as bowel, bladder or prostate cancer in men and breast, bowel or ovarian cancer in women (Stewart et al. 2001). The


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mortality within four years is 50% and in hospitalised patients with CHF the one year mortality is 40% (Dickstein et al. 2008). As a clinical symptomatic description, mild, moderate and severe CHF is used, The New York Heart Association (NYHA) functional classification, Figure 2 (The Criteria Committee of the New York Heart Association 1994). Also NYHA-class, even though a subjective measure, can predict mortality (Bouvy et al. 2003). The yearly mortality in NYHA II is 7%, 13% in NYHA III, and 25% in NYHA IV (MERIT-HF Study Group 1999). Notably, the assessment of NYHA classification performed by the clinicians does not correlate with the patients self assessment of symptoms (Ekman et al. 2007). The NYHA classification is used routinely in most clinical trials since it is an easy measure, however Hobbs et al. (2005) showed that NYHA classification does not always seem useful in clinical practice since only 9% primary care physicians in Sweden know what the classification means and of these less than half use it. Correlations between NYHA-class and the 6 minute walk test is clear (Dawn & Haennet 2000) and also health-related quality of life correlates very well to NYHA-class where NYHA-class I has less impact on health-related quality of life and NYHA-class III has more impact (Hobbs et al. 2002, Juenger et al. 2002).

![Features of heart failure](image)

<table>
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<th>Features of heart failure</th>
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<tr>
<td><strong>Symptoms typical of heart failure</strong></td>
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<tr>
<td>Breathlessness at rest or exercise, fatigue, tiredness, ankle swelling</td>
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<tr>
<td><strong>Signs typical of heart failure</strong></td>
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<tr>
<td>Tachycardia, tachypnoea, pulmonary rales, pleural effusion, raised jugular venous pressure, peripheral oedema, hepatomegaly</td>
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<tr>
<td><strong>Objective evidence of a structural or functional abnormality of the heart at rest</strong></td>
</tr>
<tr>
<td>Cardiomegaly, third heart sound, cardiac murmurs, abnormality on the echogardiogram, raised natriuretic peptide concentration</td>
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Figure 1. Definition of CHF adopted from Dickstein et al. (2008).
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Figure 1. Definition of CHF adopted from Dickstein et al. (2008).

<table>
<thead>
<tr>
<th>Class I</th>
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<tr>
<td>♦ Symptoms typical of heart failure</td>
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<tr>
<td>♦ Breathing at rest or exercise, fatigue, tiredness, ankle swelling</td>
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<th>Class II</th>
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<tr>
<td>♦ Signs typical of heart failure</td>
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<tr>
<td>♦ Tachycardia, tachypnoea, pulmonary rales, pleural effusion, raised jugular venous pressure, peripheral oedema, hepatomegaly</td>
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<th>Class III</th>
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<tr>
<td>♦ Objective evidence of a structural or functional abnormality of the heart at rest</td>
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<th>Class IV</th>
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<tr>
<td>♦ Unable to carry on any physical activity without discomfort. Symptoms at rest. If any physical activity is undertaken, discomfort is increased.</td>
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Figure 2. NYHA functional classes and severity based on symptoms and physical activity adopted from The Criteria Committee of the New York Heart Association (1994).
Physical function

Definition of physical fitness, physical activity and exercise

Every human being performs some form of physical activity (Caspersen 1985) and physical function is one of the most important components in quality of life (Bowling & Gabriel 2004). Even though participation and maintenance of regular physical activity is recognised as one of the most important health behaviours in preventing onset of or reducing the severity of many chronic diseases, the prevalence of physical inactivity is highest among the older (Patla & Shumway-Cook 1999) where also CHF is most prominent. However, lay people and healthcare professionals probably have different preferences and use different expressions and definitions when discussing physical fitness, physical activity and exercise and it is important to be aware of the difference between them.

Physical fitness is a set of attributes that people have or achieve and being physically fit includes five health related components of physical fitness: cardio-respiratory endurance, muscular endurance, muscular strength, body composition, and flexibility. Physical fitness can range from high to low and is a state of well-being that allows one to meet the demands of daily living.

Physical activity is defined as all bodily movement that is produced by skeletal muscles and results in energy expenditure. Everyone performs physical activity in order to sustain life, but the amount is up to personal choice and may vary considerably between patients, but also in the same patient over time. Physical activity in daily life contains activity in occupation, sports, conditioning, household or other activities. Physical activity can also be divided into light, moderate or heavy intensity.

Exercise is a part of physical activity and is planned, structured, repeated and aimed at retaining or improving physical fitness. This definition includes that it is supposed to improve or maintain components of physical fitness rather than achieve or maintain an established level. With this definition it is not needed to establish the achievements necessary to become physically fit since it will vary, at least by sex and age (Caspersen et al. 1985).
Physical fitness and physical activity when having chronic heart failure

In advancing age, functional capacity in performing advanced and even basic activities of daily life becomes limited (Topinková 2008). In the elderly who additionally live with CHF which is associated with impairment of exercise capacity and functional ability (Hutcheon et al. 2002) these limitations are even more prominent. Elderly patients with CHF describe an inability to be as efficient as wanted, inability of being of use to themselves or others as wished for and experience such a lack of physical strength that feelings of uselessness emerge (Ekman et al. 2000). Also, patients with CHF experience a loss of formerly pleasurable activities when experiencing a functional loss (Turvey et al. 2003). Patients suffer from fatigue and dyspnoea and this restricts their ability to perform activities of daily life which often results in a decrease in quality of life (Ford et al. 2004). Physical inactivity is common in patients with CHF and this contributes to progression of the syndrome (Graham et al. 2007). Many healthy elderly people are at or near the functional threshold for dependence and thereby in jeopardy of losing the capacity to carry out activities of daily life. With worsening of musculoskeletal fitness an elderly individual may even lose the capacity to climb stairs or get out of a chair (Warburton et al. 2001a). Elderly people who live calm lives may not perform activities that incur fatigue or dyspnoea, making these non-specific symptoms less noticeable (Jurgens et al. 2009). Many activities of daily life do not require a large aerobic output, but depend on more of the musculoskeletal fitness which is why musculoskeletal fitness appears to be particularly important for elderly and their ability to maintain functional independence (Warburton et al. 2001a, Warburton et al. 2001b).

Exercise when having chronic heart failure

Patients with CHF suffer from reduced exercise capacity and are limited in their physical activities in daily life due to fatigue and dyspnoea. Exercise intolerance is caused by reduced cardiac output, elevated intrapulmonary pressure, skeletal muscle changes, inactivity, under-perfusion and increased levels of neurohormones (Kokkinos et al. 2000). Both the CHF and the peripheral organ injuries account for the exercise intolerance in the patient
(Tabet et al. 2009). On the other hand, risks from physical exercise are small which is why physical exercise ought to be offered to the patients in NYHA-class I-III as a part of the treatment plan (Dickstein et al. 2008). It is shown that even in NYHA-class IV the safety in symptom-limited exercise is high when patients are treated in accordance to guidelines (Keteyian et al. 2009). The knowledge of exercise in NYHA-class IV is however scarce. Exercise, no matter the aetiology of CHF is of benefit to the patient (Davies et al. 2010), but there is a conception in lay persons that exertion is not of benefit when having CHF (Remme et al. 2005) which might negatively influence the physical activity in daily life in patients with CHF. To reassure and help the patient to be comfortable about physical activity, understand the benefits of exercise and perform exercise regularly is an important task for healthcare professionals (Dickstein et al. 2008). A primary goal of rehabilitation is to develop the necessary skills to independence (Patla & Shumway-Cook 1999) and a rehabilitation program of sufficient duration with skilled professional supervision is required to overcome fear and other perceived barriers to engaging in a regular program of physical activity (de Backer et al. 2003). Exercise programmes and recommendations of levels of physical activity are becoming part of the treatment of patients with CHF in NYHA-class I-III (Dickstein et al. 2008) and patients in NYHA class II and III show similar physiological response to regular exercise as seen in healthy subjects (Coggan et al. 1992). When patients develop greater exertion tolerance less fatigue and dyspnoea is experienced. They become more comfortable performing activities of daily life which in turn leads to increased independence, less depression and an improved general sense of well-being (Working Group on Cardiac Rehabilitation and Exercise and Working Group on Heart Failure 2001). The main goal of exercise is to improve physical activity and exercise is shown to increase VO2 (van Tol et al. 2006), quality of life, distance walked in the 6 minute walk test (Karapolat et al. 2009, van Tol et al. 2006), increase the amount of daily activities (Witham 2007), and increase the daily function of the patients that attended exercise (Witham 2008). Further, depression symptoms (Karapolat et al. 2009) and anxiety levels declined significantly (Witham 2007). Aerobic exercise (van Tol et al. 2006) as well as peripheral muscle training (Delagardelle & Feiersen 2005, Davies et al. 2010) are beneficial in patients with CHF. Aerobic exercise mainly affects the central circulatory system and is commonly used in
exercise in patients with CHF (Davies et al. 2010) and peripheral muscle training is a method of exercising with high relative load on individual muscle groups while maintaining low central circulatory stress levels. The resistance for muscles and/or cardiovascular systems should be kept on maintenance level or harder than normal and exercise benefits are maintained or improved as long as the exercise is habitual (Wilmore 2004). The majorities of studies in the area of CHF are in young patients (Dickstein et al. 2008) and have used hospital based exercise. Literature in home based exercise (mostly arranged from hospital) is however increasing, especially during the last decade. Inconclusive results are shown with beneficial effect of distance walked (Corvera-Tindel et al. 2004) and health-related quality of life (Oka et al. 2000) or neutral effect of distance walked (Jolly et al. 2009, Dracup et al. 2007) and health-related quality of life (Dracup et al. 2007). The literature in home based exercise in elderly patients with CHF is scarce.

Being a spouse

Being a spouse to someone with chronic illness

In the past it was considered as a natural part of life to take care of a sick partner. This was changed in the middle of the 20th century when professional carers in hospital settings took this responsibility and spouses were placed in the background often having the role as a passive bystander. During the last decades shorter lengths of stays in hospital has become normal and a change has emerged towards spouses once again having to take a bigger responsibility for their loved ones. A considerable demand is experienced in spouses when chronic disease or illness afflicts the loved one. The diagnosis of a chronic disease or illness in the loved one may cause physical and emotional alterations together with fear and uncertainty in relation to the future. However, a changed but endurable lifestyle of the spouse is described by Eriksson & Svedlund (2006) and giving it up was considered to be a disaster and life would be meaningless. Spouses of chronically ill patients in general feel burdened especially when patients have a bad prognosis (Kriegsman et al. 1994). The burden of caregiving can be defined as perceived overload in the physical, psychological, social or
financial perspectives (Chou 2000). It is known that providing care in a chronically ill family member even contributes to physical morbidity in spouses when they are caregivers (Pinquart & Sorensen 2003, Vitaliano et al. 2003).

**Being a spouse when the loved one is having chronic heart failure**

Since CHF affects approximately 10-20% of the elderly (Dickstein et al. 2008), a considerable part of the elderly population lives close to such a person and spouses might take an informal caregiving role. This means that those many times least able to care for someone with CHF are forced to cope with managing complex therapeutic regimens and assisting in activities of daily life. Despite advances in technology, improved pharmacological therapies, and patient education, CHF remains a progressively debilitating disease for many patients and their spouses. Spouses indicate serious negative changes in everyday life, such as difficulties in household tasks and worsened emotional well-being (Bakas 2006), serious impact on the relationship with the partner (Luttik et al. 2007) and lower general health than spouses of healthy partners, regardless of gender (Luttik et al. 2009). Better understanding of spouse caregiver burden and its determinants is essential to identify and support spouses that are at risk since the patient’s disease severity is not solely important related to caregiver burden (Luttik et al. 2009). Nearly half of the spouses, when the loved one is having CHF, report insufficient perceived control over the loved ones’ CHF (Bakas et al. 2006). Accurate information about how to perform CHF self-care maintenance and management to both members of the couple could improve both the relationship quality and CHF self-care (Sebern & Riegel 2009) and disagreement about care experiences increases strain and depressive symptoms in both members of the couple (Lyons et al. 2002).
Management of chronic heart failure

Health care

In the past 15-20 years the non-pharmacological and pharmacological treatment of CHF has undergone a tremendous development. The treatment consists of a complex regimen of medication, fluid restriction, dietary prescriptions, symptom monitoring, exercise recommendations and self-care which are one part of successful CHF treatment. Medications are intended to counteract the pathophysiological mechanisms and much new information related to treatment of CHF has emerged through the years. The purpose of CHF management is to reduce the morbidity and mortality, however, in the elderly, also reduce symptoms, reduce hospitalisation, and to help the patients to live an independent life are goals that could be as important as the goal of maximising the duration of life (Dickstein et al. 2008). A wide range of medications is used in CHF which all can give more or less negative side-effects that have implications in the daily life of the patient. Following the complex regimen affects the lives of both patients and spouses and the couple must be encouraged to have a healthy lifestyle, but also to continue as much as possible of the physical and social activities that were a part of life before the syndrome occurred. The interruption of daily life in combination with the fact that all medical treatment is non-curative probably makes the adherence to the regimen more difficult than if a cure is possible. CHF management programmes worldwide have key components, such as an objective diagnosis verified by echocardiography, early follow-up after hospitalisation and increased access to care provided by nurses and physicians or a multidisciplinary team. The programmes have the objectives to provide optimised drug therapy due to guidelines, patient education and counselling with special emphasis on self-care, as well as psychosocial support to the patient and spouse (Jaarsma et al. 2006). Education of patients is one part of CHF management and comprises general advice, drug counselling, counselling about the relationship between activity, exercise and rest, dietary and social habits, and symptom assessment and management (Vilaseca et al. 2008) which can help the patient to understand
why the non-pharmacological and pharmacological treatment is of importance. Since the goal of education is to help the patient and spouse to make informed choices and reach the goals regarding self-care (Strömberg 2005) the whole couple must be involved in the education provided. Healthcare professionals in general and nurses in particular have the responsibility to support, guide and educate patients and spouses in line with research and guidelines with the goal of enabling the couple to carry out self-care in the situation they find themselves. Nurse-led follow-up in patients with CHF is shown to improve survival and reduce readmission rates (Roccaforte et al. 2005, McAlister et al. 2004, Strömberg et al. 2003), improve health-related quality of life (Roccaforte et al. 2005, McAlister et al. 2004), as well as self-care behaviour and reduce the number of days in hospital (Strömberg et al. 2003). One study showed that even if there is strong evidence, only a minority of all CHF patients access specialised multidisciplinary CHF management (Clark et al. 2007). In Sweden, elderly patients are more often referred to primary care for follow-up (Swedish Heart Failure Registry 2008), i.e. a majority of hospitalised patients with CHF need to be primarily taken care of in primary care for follow-up. Primary care is often also responsible for secondary follow-up for the patients initially taken care of in specialised care in the near future.

**Primary care**

The demands of expanded service in primary care have increased since the number of individuals living with CHF is rising (Agvall et al. 2005) and an improved survival trend has been concluded (Schaufelberger et al. 2004). The primary care is different between different countries and primary care centres in Sweden most often consist of different professions, such as general practitioners, nurses, physiotherapists, occupational therapists, dieticians, etc. making a multidisciplinary care possible. Due to The Health and Medical Service Act (1982:763, p. 7), ‘primary care as a part of outpatient care shall, with no restriction as to illness, age or patient categories, cater to the need of the population for such basic medical treatment, nursing, preventive work and rehabilitation as do not require the medical and technical resources of hospitals or other special competence.’ Primary care has a holistic approach (Socialstyrelsen 2004) which is seen as
knowledge of the individual, whose diseases or illnesses come and go, in contrast to the secondary care which has a more narrow sight of diseases, and individuals come and go. Most patients with CHF are taken care of in primary care with regard to long-term follow-up (Shakib et al. 2009, Agvall et al. 2005) with no further cardiac specialist appointments (Shakib et al. 2009). However, elderly patients in primary care are not always taken care of in line with the best knowledge from research in regard to medication (Dahlström et al. 2009) and lifestyle, which could be a result from the lack of elderly patients in research. The specialised knowledge in CHF management in hospitals is not always transferred to primary care and further management in primary care after hospitalisation of CHF was recorded in only 10% of discharge letters and non-pharmacological recommendations, for example exercise plans, regular weight monitoring or diuretic action plans were not found (Shakib et al. 2009). Specially organised care of patients with CHF in primary care is remarkably few considering the evidence for its benefits in hospital settings. In the year 2005 less than one fifth of primary care centres in Sweden had nurse-led follow-up of patients with CHF whereas nurse-led follow-up in diabetes and asthma/chronic obstructive pulmonary disease were present in 93% and 78% of primary care centres respectively. Significantly more information on the CHF topic, such as information/education in self-care and adjustments of medication was provided to patient and spouse in primary care centres where nurses had dedicated time in CHF follow-up (Mårtensson et al. 2009). Primary care needs to play an increasing role in the management of CHF since prevention and management of chronic diseases in general are shown to be best performed by multidisciplinary teams in primary care (Bodenheimer at al. 2009). Countries with well-developed primary care have the potential to deliver coordinated care for patients with advanced long-term conditions and deterioration due to deficits in self-care which ought to be possible to prevent that gives positive effects in life of patients and spouses.

**Daily life activities and self-care**

To be part of daily life activities is important to most people and should be one of the goals in CHF care. There is no clear definition comprising the content of activities of daily life, probably due to the different preferences in
the lives of different people. However, there is one definition of activities of daily living including three components: the communication skills and mobility skills required for independence in everyday life and self-care (APTA 2004). In this thesis, the phrase ‘activities of daily life’ is used as something more than activities of daily living. It also comprises activities necessary to be content in life. In CHF there is a range of personal, environmental and social factors that may limit the ability to perform physical activities (Bennett et al. 2005); however, activities of daily life are not always limited only by physical symptoms. There are patients that perform activities of daily life well below that of their true exercise capacity (van den Berg-Emons et al. 2005). The exercise capacity has been shown to be improved by a number of different therapies (Meyer & Laederach-Hofmann 2003, Hutcheon et al. 2002, McKelvie et al. 2002), but normal activities of daily life appear to be more difficult to influence with these therapies (van den Berg-Emons 2004, Willenheimer et al. 2001); however, the scientific descriptions are scarce.

WHO (1983, p.6) defines self-care as “activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health”. In the area of CHF, self-care is further described as a naturalistic decision-making progress involving the choice of behaviours that maintain physiologic stability, prevent acute exacerbations, promote self-care maintenance and self-care management, the possibility to respond in order to evaluate and finally effectively alleviate symptoms when they occur, see Figure 3 (Riegel & Dickson 2008, Riegel et al. 2004). Patients with CHF are responsible for the majority of their own care (Lee et al. 2009, Riegel & Dickson 2008) and disease management education is one way to build confidence in self-care knowledge and skills (Riegel & Carlson 2004) and encourage patients to take an active role in managing their disease. Self-care is a part of successful treatment of CHF and can significantly impact physical capacity, well-being, symptoms, morbidity and prognosis (Jaarsma et al. 2003). When patients get older or develop a chronic illness the self-care becomes more difficult and time consuming and when the patients could benefit the most from self-care the self-care efforts may fail (Moser & Watkins 2008). Decreased physical function in CHF negatively affects the ability to perform self-care since physical limitations and debilitating symptoms are shown to impede
effective self-care (Lee et al. 2009) and better functional status is a significant determinant of self-care maintenance (Riegel et al. 2009). Since patients with CHF and spouses handle most of the care outside health care settings the self-care capability of the couple must be strengthened and physical limitations minimised. The complexity and collection of symptoms associated with CHF cause both functional and cognitive impairments that contribute to the challenge of living with this chronic illness (Wolfe et al. 2006, Bennett et al. 2005). Patients with CHF are known to discount the early symptoms of decompensated CHF as normal ageing (Patel et al. 2007), but interpretation and response to symptoms are also affected by the social and emotional context in which they occur (Horowitz et al. 2004). One explanation of this phenomenon may be that elderly patients struggle with more symptom recognition because of age-related changes in interception with CHF (Patel et al. 2007). Spouses have an important role to play since they also recognise and interpret symptoms of the patient and treatment and management of CHF is often done with help from a family member (Moser & Watkins 2008). However, with a preserved physical function the self-care maintenance is kept high which provides early recognition of symptoms. The confidence in the ability to perform CHF self-care (self-care confidence) is important (Riegel et al. 2004) and influences the relationship between self-care and clinical outcomes (Riegel & Dickson 2008) since patients believe in their ability to handle self-care and in the prolongation of activities of daily life. Predictors of self-care and achievement of therapeutic goals include physical factors, such as increasing age (Chriss et al. 2004), co-morbidity (Chriss et al. 2004, Artinian et al. 2002), and psychological factors, such as social support (Sayers et al. 2008) whereas depressive symptoms is a barrier to self-care (Schnell et al. 2006).
Definitions of health-related quality of life

Quality of life is often used to summarise the life situation and well being in individuals. The World Health Organisation defines quality of life as “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns, it is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment” (The WHOQOL Group 1995, p. 1405). According to this definition, quality of life deals with what makes life worth living and what makes a good life for the person living it. The goal of raised or preserved quality of life is of highest importance for chronically ill, especially when a cure is no longer possible (MacMahon & Lip 2002).

In the healthcare area quality of life usually concentrates on one component of quality of life, the health-related quality of life. Health-related quality of life implies the way in which physical, emotional and social well-being are affected by a disease or its treatment (Fairclough 2001) and can be seen as the individual’s interpretation of his/her status in comparison to what he/she hoped or expected it to be. No clear definition exists on health-related quality of life, but an international group of health-related quality of life
investigators has reached an agreement on fundamental dimensions essential to any health-related quality of life assessment. The dimensions include physical-, psychological-, and social functioning as well as financial aspects, and the patient’s overall life satisfaction and perceptions of health status (Masoudi et al. 2004).

**Health-related quality of life when having chronic heart failure**

CHF is impairing health-related quality of life more than almost any other chronic disease (Hobbs et al. 2002) and patients with CHF report more severe physical impairment than those with chronic lung disease or arthritis (Hobbs et al. 2002, Juenger et al. 2002). The importance of health-related quality of life in CHF patients is even more highlighted by the fact that some patients may be willing to trade survival for improved quality of life (Lewis et al. 2001, Rector at el. 1995) and low health-related quality of life is a marker for morbidity and mortality (Johansson et al. 2006). The most common definition of health-related quality of life as perceived by patients with CHF is the ability to perform physical and social activities (Heo et al. 2009) and the physical dimension of health-related quality of life is most affected in elderly patients with CHF which leads to a negative impact in daily life (Franzén et al. 2007, Franzén et al. 2006). The syndrome has an important impact on the ability of patients to perform their usual activities (Calvert et al. 2005) which affects the spouse as well. Dissatisfaction with the activities of daily life is associated with worse health-related quality of life (van den Berg-Emons et al. 2005) and even with optimised therapy the patients remain limited by symptoms while their functional capacity and health-related quality of life may be substantially reduced (Calvert et al. 2005). Difficulties in performing recreational pastimes also have an impact on daily life in elderly patients with CHF (Franzén et al. 2006, Calvert et al. 2005). Health-related quality of life does not merely reflect objective clinical or physiologic status (Clark et al. 2003, Juenger et al. 2002), but also reflects the subjective perception of the impact of clinical condition in the patient’s life (Sneed et al. 2001, Scott 2000). Health-related quality of life is sometimes being evaluated as negative because of limitations in daily activities in comparison with previous condition (Heo et al. 2009). Because
the lack of a cure in CHF health-related quality of life is used by healthcare research as a complementary end point to mortality and morbidity.

Anxiety and depression

Definition of anxiety and depression

The prevalence of anxiety and depression is approximately ten percent respectively in patients visiting primary care (Kroenke et al. 2007, Olfson et al. 1997). Anxiety symptoms include feelings of easy fatigability, trouble concentrating, irritability, and sleep disturbance (American Psychiatric Association 1994), Table 1, symptoms also present in CHF. Anxiety can range from normal to pathologic (Barlow 1998) and is an adaptive process until its magnitude or persistence gives dysfunctional response that can give negative consequences to the patient. When having anxiety the patient’s worries focus on the safety and comfort of the family and oneself with the worries being future oriented (Allgulander 2010). The prevalence of anxiety disorder is much lower than that of anxiety symptoms (Beekman et al. 1998). Anxiety symptoms in very old people are present in one fourth of the population where they report feeling anxious “now and then” or “most of the time” (Forsell & Winblad 1998). Increasing anxiety severity in elderly patients is correlated with the degree of disability and health-related quality of life. Patients with generalised anxiety disorder report significantly less frequent engagement, participation restriction, and more difficulty, activity limitation, in everyday activity than healthy comparisons (Porensky et al. 2009).

There is an association between anxiety and depression; however, it is not possible to address the directionality of the relationship (Bryant et al. 2008). In contrast to anxiety, depression handles past failures and is associated with guilt feelings (Allgulander 2010). Depression in elderly is a serious medical condition (Steffens 2009) and clinical depression interferes with a person’s ability to perform activities of daily life (Seligman 1998). In older age, those who report being more physically active have higher levels of energy and vitality and lower levels of depression (Abu-Omar et al. 2004). Further, in elderly persons, depression is correlated with increased risk of physical
dysfunction even after control of physical diseases and earlier functional decline (Kivelä & Pahkala 2001). Moreover, depression is associated with poor self-care (Cameron et al. 2009, Jerant et al. 2008) necessary when having CHF. Depression is defined by the presence of a specific group of affective, cognitive, psychomotor and somatic symptoms, Table 1. The two affective symptoms, a depressed, sad mood and loss of interest or pleasure in nearly all activities, i.e. anhedonia, are the core symptoms of depression. The amount of symptoms gives different depression severity as in mild or major depression. In major depression the patient suffers from at least one core symptom and at least four of the cognitive, psychomotor or somatic symptoms, whereas minor depression involves a maximum of four symptoms, one of which must be a core symptom, however, not as pronounced as in major depression (American Psychiatric Association 1994). In older adults a protective effect of physical activity on development of depression is reported (Strawbridge et al. 2002). From the literature above it seems that the association between depression and physical activity is probably bidirectional with physical inactivity leading to depression and depression leading to inactivity. The mutual influence between functional capacity and depressive symptoms in the elderly is considered to reinforce each other over time (Ormel et al. 2002).
Table 1. Depression and anxiety symptoms adopted from the American Psychiatric Association (1994).

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Depression</th>
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<tbody>
<tr>
<td><strong>Cardinal feature</strong></td>
<td><strong>Affective symptoms (core symptoms)</strong></td>
</tr>
<tr>
<td>- Generalised persistent anxiety for at least one month</td>
<td>- Depressed dysphoric mood</td>
</tr>
<tr>
<td></td>
<td>- Anhedonia, loss of interest or pleasure in almost all usual activities and pastimes</td>
</tr>
<tr>
<td><strong>Other anxiety symptoms</strong></td>
<td><strong>Psychomotor, cognitive and somatic symptoms</strong></td>
</tr>
<tr>
<td>- Feelings of restlessness</td>
<td>- Weight loss or weight gain, or decrease or increase in appetite</td>
</tr>
<tr>
<td>- Muscle tension</td>
<td>- Insomnia or hypersomnia</td>
</tr>
<tr>
<td>- Heart pounding</td>
<td>- Psychomotor agitation or psychomotor retardation</td>
</tr>
<tr>
<td>- Dizziness</td>
<td>- Fatigue or loss of energy</td>
</tr>
<tr>
<td>- Easy fatigability</td>
<td>- Feelings of worthlessness or guilt</td>
</tr>
<tr>
<td>- Anticipating that something bad will happen</td>
<td>- Diminished ability to think or concentrate or ambivalence</td>
</tr>
<tr>
<td>- Irritability</td>
<td>- Thoughts of death or suicidal ideation</td>
</tr>
<tr>
<td>- Sleep disturbance</td>
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</table>

**Anxiety and depression when having chronic heart failure**

Anxiety in patients with CHF is scarcely described in literature; however anxiety in patients with CHF is extra strong at the time of changes of symptoms or treatment when the symptoms are shown for the first time or when care is inconsequent (Winters 1999). This means that the degree of anxiety experienced by the patient relates to the degree of uncertainty of the disease process. On the other hand when the diagnosis is confirmed and symptoms are stable and identified the anxiety is diminishing (Winters 1999). The prevalence of depression in CHF patients is approximately 22% (Rutledge et al. 2006) and among outpatients with CHF, depression rates from 13% (Skotzko et al. 2000) to 48% (Gottlieb et al. 2004). The differences in reported prevalence can be explained by the use of different methods where patient perceived depression, measured in questionnaires,
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Anxiety and depression when having chronic heart failure

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**Rationale**

CHF influences the life-situation in the whole couple. Activities of daily life and health-related quality of life are impaired and the reasons for these limitations are mostly described as physical limitations. The complex syndrome affects more and more patients and thereby spouses, especially in higher age and the physical limitation, frequent hospitalisations, role changes, and disruption of the usual sources of social support characterise the course of the syndrome and can cause stress in the couple. The high age makes the normal ageing process afflict both members of the couple and in addition, CHF makes help most needed when the spouse also might be old and frail and the least capable to support the patient. Despite optimal medical treatment, however rarely reached in elderly patients with CHF in primary care, the patients perceive that they are limited in their physical activity. Health-related quality of life in the patient is closely connected with the ability to perform physical and social activities. There is most often no cure to CHF which means that health-related quality of life is of greatest importance, especially since patients are willing to trade survival for health-related quality of life. The overall treatment plan of CHF must reinforce enhanced health-related quality of life and independence in the couple and break a vicious circle of inactivity and decreasing physical capacity in the patient.

The majority of care in CHF is done by patients and spouses, i.e. self-care which is negatively influenced by physical limitation. Patients with CHF often change between high possibilities for self-care and suddenly in times of deterioration the self-care diminishes in favour of spouses. To meet these needs of the patient, the spouse must have the knowledge and confidence to guide and support the loved one. Spouses on the other hand are burdened and perceive negative changes in daily life due to the syndrome in the loved one. Higher physical demands have become a part in life since the loved one is no longer able to participate in the daily tasks of the couple. Spouses are important in the life of the patient with chronic diseases or illnesses and CHF.
is no exception. More responsibility regarding the care in chronic diseases has been transferred to the couple and over the decades the caregiver role of the spouse has changed with increased strain on the spouse. Previous research in spouses provides scarce in depth insight into how CHF affects elderly spousal caregivers’ lives or which aspect of the caregiving role specifically influences the spouse’s well-being and quality of life.

Physical requirements are not the same in different patients since the patient’s preferences vary in this matter; however it is necessary to evaluate the patient’s needs and spouse’s possibilities in daily life activities. Elderly patients with CHF usually do not have a work as a profession to perform, but have an urgent need to be physically fit to withstand a daily life together with the spouse. Also, physical impairment predicts anxiety and depression which is more common in CHF than in a population without CHF and even other chronic diseases or illness. Anxiety is negatively correlated with the degree of health-related quality of life and perceived disability and depression affects the possibilities of day to day living.

Risks from physical activity and exercise are small in CHF and exercise is of benefit even if the patient has not performed exercise before. Exercise has become a natural part of the treatment plan in hospital settings in mostly younger patients, but it is not common in the elderly patients with CHF in primary care even though this is the large population of CHF. The limited public resources makes the elderly patients not prioritised in the secondary care in hospital which implies that appropriate CHF care should be given in primary care, including exercise. Another reason, apart from the healthcare point of view, an important gain of exercise as a part of primary care is due to logistic problems in the patients and couple. Patients have trouble with transportation to the hospital in order to exercise. Since the patients are getting older and more of them are diagnosed and treated in primary care it is important, in these settings, to take care of both the patient’s needs and the needs of knowledge and confidence in the couple. Even if exercise is proven beneficial there is a lack of evidence in this topic in certain groups, for example, elderly patients.

Healthcare professionals in primary care must gain knowledge about patients’, spouses’ and couples’ experiences of health-related quality of life and daily activities and how physical factors, such as physical deterioration relates to this in order to in a reflected way validate what kind of
intervention the patient and spouse, i.e. the couple, needs. This includes exercise and not only prescribing treatment out of earlier experiences, but with evidence from research.
Main aim of the thesis

The general aim of this thesis was to explore and describe couples’ experiences of patients’ physical limitation in activities of daily life and evaluate the effects of an exercise programme in primary care when having CHF.

The specific aims of the different studies were:

- to determine if elderly patients suffering from CHF and their spouses experience similar levels of health-related quality of life and depression and to identify factors that contribute to health-related quality of life in patient-spouse pairs. (I)
- to describe how patients suffering from CHF conceive their physical limitations in daily life activities. (II)
- to explore and describe how spouses conceive the physical limitations in patients with CHF and the impact these limitations have on the daily life of the spouse. (III)
- to determine the effects on physical capacity and health-related quality of life of an exercise programme in elderly patients with CHF in primary care. (IV)
Material and methods

Epistemological and ontological frame

There is no easy way to understand the complex world of a patient or spouse. Nursing research addresses problems important to clinical practice and the research encompasses the range of human responses to health and illness, including biological and psychological manifestations as well as emotional, motivational, psychological and social facets (Risjord et al. 2001). In order to give a more comprehensive picture of the phenomenon investigated both qualitative and quantitative research is combined. The thesis comprises both inductive, the path of discovery, and deductive, the path of clarification, research as it is both an explorative and interventional study. The health of a patient and spouse can be based on an understanding from the complex indivisible whole, i.e. holistic approach, as well as the parts, i.e. positivistic approach, at the same time. Even though the two approaches, holistic and positivistic, are rooted in different epistemological and ontological positions (Denzin & Lincoln 1994), they should not be seen as dichotomies.

Qualitative studies are aimed to be holistic and have a common goal of understanding. Phenomenography, the methodological approach used, aims to find the variation of the world as experienced by patients and spouses (Sjöström & Dahlgren 2002) and in qualitative research the researcher seeks to understand the entire complex picture that can not be meaningfully reduced to a few discrete variables or linear cause-and-effect relationships (Patton 2002). The ontological reality in holistic approach means striving for an understanding of the patient or spouse, as a whole, and the meaning and knowledge derives from the patients’ or spouses’ perceptions. Knowledge about humans is not possible without the understanding of the experience as it is perceived and characterised by the person that lived the experience. Phenomenography is a set of assumptions about knowledge of other person’s ways of experiencing the world and the only world that can be communicated is the world experienced (Marton 1988). A researcher with phenomenographic approach is primarily interested in how the phenomenon
is perceived and not how the world really is and the epistemological assumption is that humans differ as how the world is experienced. However these differences can be described, communicated and understood by others (Marton 1988). The researcher interacts with the patient being studied through interviews or observations and findings are created in an interactive process (Polit & Beck 2010) which allows the researcher to study phenomenon more in depth and in detail than with questionnaires.

A positivistic approach ontologically sees human beings as the sum of their parts and strives to be as objective as possible when pursuing knowledge and the parts instead of the whole are examined. Epistemologically, the researcher strives to stay objective towards the participants during the data collection. The researcher can influence the choice of variables but the findings of the measures are not influenced (Polit & Beck 2010).

The holistic approach was the beacon through the thesis and the positivistic approach was used to be able to add another bit of the puzzle to the research phenomena of physical limitation.
Design and settings

Overview

Design and analysis approach

The complexity of the world of a patient with CHF and their spouse is not easy to understand. In this thesis the qualitative, inductive and quantitative, deductive approach was used to increase the researchers’ possibility to give a more comprehensive picture of the studied phenomenon, physical limitation in the patient with CHF. The thesis includes one comparative study that aimed to compare levels and identify contributing factors of health-related quality of life and depression in patients and spouses (Study I), two qualitative studies that aimed to explore and describe conceptions of physical limitations of the patient in daily life activities from a patient perspective (Study II) and spouse perspective (Study III) and finally an intervention study that aimed to determine whether an exercise programme in primary care effects physical limitation, physical capacity and health-related quality of life (Study IV). An overview of the relationship between studies is presented in Figure 4. The research phenomenon in this thesis admitted and required a combination of methods and approaches. The most obvious advantage of such a combination of methods, called triangulation, is the complimentary strengths and weaknesses of chosen methods (Polit & Hungler 1999). Five different types of triangulation are described: data triangulation, investigator triangulation, theoretical triangulation, methodological triangulation (Denzin 1978) and interdisciplinary triangulation (Denzin & Lincoln 1994). When combining more than one of these types of triangulation, multiple triangulation is used (Burns & Grove 2005). In this thesis triangulation was used to illuminate different aspects and dimensions of physical limitation when having CHF and thereby a deeper understanding can be reached.
In this thesis, the qualitative, inductive and quantitative, deductive approach was used to increase the researchers' possibility to give a more comprehensive picture of the studied phenomenon, physical limitation in the patient with CHF. The thesis includes one comparative study that aimed to compare levels and identify contributing factors of health-related quality of life and depression in patients and spouses (Study I), two qualitative studies that aimed to explore and describe conceptions of physical limitations of the patient in daily life activities from a patient perspective (Study II) and spouse perspective (Study III) and finally an intervention study that aimed to determine whether an exercise programme in primary care effects physical limitation, physical capacity and health-related quality of life (Study IV). An overview of the relationship between studies is presented in Figure 4.

Figure 4. Overview of studies and their relationships in the thesis. The continuous lines show the relations between the studies, but also the qualitative studies influenced Study IV, however, not in a direct way which is why these arrows are crosshatched.
Participants and setting

In Study I all participants were recruited from primary care in one county council in the southern part of Sweden. Participants in Study IV were recruited from primary care in three different county councils. The county councils were similar with respect to size and citizens in the catchment area. In all three county councils the majority of primary care was organised in the public service. Study II and III were performed in one county council in the southwest of Sweden and the participants were recruited with help from a CHF specialist nurse in the CHF ward. See Table 2 for clinical characteristics and sociodemographic data of patients and spouses in all four studies.

Table 2. Clinical characteristics and sociodemographic data of patients and spouses in all four studies.
P= Patient, S= Spouse, I= Intervention, C= Control

<table>
<thead>
<tr>
<th>Study</th>
<th>P</th>
<th>S</th>
<th>I</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>47</td>
<td>47</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
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<tr>
<td>Mean age</td>
<td>78</td>
<td>75</td>
<td>76</td>
<td>74</td>
</tr>
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<td>13/34</td>
<td>10/5</td>
<td>10/5</td>
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<td>Civil status, n</td>
<td>Married/ Co-habiting</td>
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<td>47</td>
<td>9</td>
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<td>4</td>
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<tr>
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Participants and setting

In Study I all participants were recruited from primary care in one county council in the southern part of Sweden. Participants in Study IV were recruited from primary care in three different county councils. The county councils were similar with respect to size and citizens in the catchment area. In all three county councils the majority of primary care was organised in the public service. Study II and III were performed in one county council in the southwest of Sweden and the participants were recruited with help from a CHF specialist nurse in the CHF ward. See Table 2 for clinical characteristics and sociodemographic data of patients and spouses in all four studies.

Table 2. Clinical characteristics and sociodemographic data of patients and spouses in all four studies.

<table>
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<tr>
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Study I

Population

A total of 47 patients in primary care and their spouses were included. Inclusion criteria were diagnosed CHF based on echocardiography, radiographic evidence of pulmonary congestion or typical symptoms, signs of CHF and NYHA-class II-IV, age over 60 years and resident in the catchment area. Spouses were included if they lived in the same household as the patient. Patients and spouses were excluded if they had dementia or other psychiatric illness expected to affect the study outcome or had difficulties in reading and understanding the Swedish language.

Questionnaires

**Short form -36**

Short Form-36 (SF-36) is a generic health-related quality of life instrument designed to assess function and well-being, as well as the use of treatment (Ware & Sherbourne 1992). The SF-36 item instrument contains 36 multiple-choice questions and includes eight domains of health-related quality of life: physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role limitations due to emotional health problems (RE) and mental health (MH). Each item is used in scoring only in one scale (Ware 2000). Higher scores indicate better health (Ware & Sherbourne 1992). The eight domains form two summary measures: the physical component score, PCS, and the mental component score, MCS (Ware et al. 1995). SF-36 is a well-established and frequently used instrument and has been found to have high reliability and validity (Ware & Sherbourne 1992, Ware 2000, Sullivan et al. 1995). The Swedish version of the SF-36 has been psychometrically tested and validated in a Swedish normal population (Sullivan & Karlsson 1998). SF-36 has been used in patients with CHF (Parish 2006, Collins et al. 2004), among other heart conditions.
Study I

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Zung self-rating depression scale

The Zung Self-Rating Depression Scale (SDS) was originally developed to quantify the severity of current depression in patients of all ages with a primary diagnosis of depressive disorder (Zung 1965). SDS comprises 20 items, ten worded positively and ten negatively. For each item the respondent indicates the frequency with which they experience the symptom or feeling (Zung 1967). The total raw SDS scores range from 20 to 80. An index for the SDS was used by dividing the sum of the values (raw scores) of the 20 items by the maximum possible score, which equalled 80. The converted SDS scores range from 0.25 to 1.0. Non-depressed individuals typically score less than 0.50, mildly depressed 0.50-0.60, moderately depressed 0.61-0.70, while the score of those with severe depression is generally higher than 0.70 (Zung 1965). SDS has high reliability (McKegney et al. 1988) and validity (McDowell 2006). Cronbach’s alpha in the present study was 0.81.

Data collection

A primary care nurse visited the patient in their homes. When verbal and written information was given, patients were asked to complete the questionnaires at home and give another copy of the questionnaire to the spouse. The completed questionnaires were returned in a stamped addressed envelope.

Data analysis

To characterise the study population, descriptive statistics were used. In the statistical evaluation, the Wilcoxon matched pair test was used to evaluate differences in depression and health-related quality of life between patients and spouses. Correlations between age, physical and mental health, and depression were evaluated for both patient and spouses, while NYHA-class was only assessed in patients. Pearson product-moment correlation coefficients were used for variables that were normally distributed and on ratio scale. Not normally distributed variables due to outliers were analysed using Spearman’s rank correlation coefficient. Univariate linear regression
was performed with age, PCS, MCS and SDS in patients and spouses and NYHA-class in patients as dependent variables, in order to identify which variables could significantly predict depression and health-related quality of life. Variables that significantly predicted depression and health-related quality of life were then included in a multivariate stepwise regression analysis to identify which combination of variables provided the most predictive power. A \( p \) value <0.05 was considered statistically significant.

In the thesis a comparison was made of health-related quality of life measured by SF-36 with age and gender matched norm populations for the patients and spouses. The norm data was obtained from the Healthcare Research Unit, Institute of Internal Medicine, Sahlgrenska University Hospital, Gothenburg University, Gothenburg, Sweden responsible for the validation of the Swedish version of SF-36.
Study II and III

Phenomenographic approach

In order to explore the qualitative variations in the participants’ conceptions of limitations in physical function of daily life a phenomenographic approach was chosen. Phenomenography was developed in the early 1970s in Sweden within the domain of learning, but has since spread from the educational context to that of health science research and is found appropriate in nursing research (Sjöström & Dahlgren 2002). This approach is based on the patient/spouse perspective and its essence is how something is conceived to be. Conceptions are the foundation in individual decision making and how people act. Phenomenography aims to describe the various ways in which people conceive the world in a cognitive way as opposed to how the world really is, resulting in a description of the variations in the way a phenomenon is experienced (Marton 1981). The experience of a phenomenon has two aspects: structural and referential. The two aspects are connected to each other and appear at the same time when something is experienced. The structural aspect refers to the fact that when people experience something, they discern its parts from the context, the way they are related to each other and the way they relate to the whole. When the whole and the parts and the relationship between them are clarified further degrees of meaning are discerned. The referential aspect is the overall significance attributed to a phenomenon and built up by means of different structural aspects that are part of the whole phenomenon (Marton & Booth 1997).

Participants

Patients (Study II) diagnosed with CHF (N=15), and spouses of patients with CHF (Study III, N=15) were strategically selected to ensure variation in social-demographic data with regard to sex, age, place of residence,
education and NYHA-class of the patient (Fridlund & Hildingh 2000) and conceptions. See list of variables in Table 2. Inclusion criteria were being a patient with CHF, diagnosed with echocardiography (Study II) or living with a loved one with CHF, diagnosed with echocardiography (Study III). Exclusion criteria were other serious physical or mental disorders in the patient (Study II and III) or the spouse (only in study III).

Data collection

Data were collected through semi-structured interviews in order to capture how patients with CHF experienced physical limitations in daily life and how spouses of patients with CHF experienced physical limitations in the loved one in daily life. Two pilot interviews were conducted; one in Study II and one in Study III, which resulted in minor changes in the interview guide. The interviews were audio-taped and transcribed verbatim.
Data analysis

The analysis was performed in accordance with phenomenography and the seven steps described by Dahlgren and Fallsberg (1991).

1. Familiarization. The interviews were read carefully to become familiar with the text.
2. Condensation. The most significant statements made by the participants were selected as representative of the entire dialogue about the phenomenon. These were viewed in the light of two parts, in relationship to other statements from other interviews and in relationship to the whole of the actual interview.
3. Comparison. All significant statements were compared in order to identify variation or agreement.
4. Grouping. Data that appeared to be similar were grouped together.
5. Articulating. A preliminary attempt was made to describe the essence of the similarity within each group of statements. Groups were then put together by analysis of the internal relations of the statements and structural aspects were formed.
6. Labelling. The various aspects were denoted by formulating an appropriate linguistic expression and referential aspects derived.
7. Contrasting. The obtained aspects were compared in terms of similarities and differences.

Steps 4 and 5 were repeated several times before the analysis was deemed satisfactory (Dahlgren and Fallsberg 1991). The referential and structural aspects that emerged were formulated to describe the context and illustrated by quotations.
Study IV

Intervention

Exercise programme

The intervention programme comprised aerobic exercise, as well as peripheral muscle training. The duration of the intervention was 12 months and was individually planned depending on the patient’s physical fitness. At two occasions after the baseline measurements the patients visited a physiotherapist in primary care oriented in exercise for patients with CHF. At the first occasion the home based exercise programme was conducted and at the other occasion the exercise programme at the primary care centre was prescribed. The amount of repetitions and the load the patients used in the exercise was approximately 75% of 1 repetition maximum (RM) and was estimated with the Borg perceived exertion scale to level 15 which is strenuous (Borg 1982). During the first six months the patients exercised once a week in a group at the primary care centre and three times a week at home. The group exercise started with common modulated warm-up exercises (10 minutes) with standing, walking and sitting exercises accompanied by music. Thereafter the patients performed their individual exercises which consisted of lower and upper body resistance training (45 minutes) and finally a period of active recovery exercises (5 minutes). The home based exercise programme (45 minutes) consisted of endurance exercise and peripheral muscle training with the resistance being regulated by a resistive elastic band (Jpm products, Hertsfordshire, United Kingdom). During the last six months of the intervention patients exercised three times a week at home and once a month in a group at the primary care centre.

Conventional care

The conventional care was performed according to local clinical guidelines in the three county councils. The local guidelines were in line with ESC guidelines (Dickstein et al. 2008).
Participants

Patients in primary care in three county councils were screened for diagnosis of CHF. A total of 59 elderly patients (13 women) with CHF were included in the study. The intervention group comprised 28 (nine women) patients and the control group 31 patients (four women). Inclusion criteria were CHF diagnosed with echocardiography and atrioventricular plane displacement <10mm or in atrial fibrillation <9mm, and NYHA-class II-III. Exclusion criteria were peripheral vessel disease, chronic lung disease, status post stroke or other disease that made the measurements for the study impossible.

Tests and questionnaires

Physical capacity

Bilateral isometric shoulder abduction

Patients sat on a stool with their back touching the wall and one kilo weight in each hand. The patients elevated both arms to 90 degrees shoulder abduction and kept this position as long as possible. When the arms started to drop, the patient was instructed to correct the position once during the test. The second time the arms started to drop the test was discontinued. The time the patient kept the shoulders at a 90 degree angle of abduction was recorded. The reliability for the test in CHF patients is very good (Cider et al. 2006).

Unilateral isotonic shoulder flexion

The patients sat on a stool with their back touching the wall holding a weight, three kilos in male patients and two kilos in female patients, in the hand of the arm to be tested. The speed was 20 lifts per minute using a metronome. The patients were asked to elevate the arm from 0 to 90 degrees flexion as many times as possible. The first time the patient did not manage to perform the test properly the patient was noticed and the second time the test was discontinued. The number of flexions was counted for each arm. The reliability for the test in CHF patients is very good (Cider et al. 2006).
6 minute walk test

The 6 minute walk test (6MWT) was first developed in the 1960s by Balke (1963) in order to evaluate functional capacity in chronic patients. The 6MWT measures the distance patients walk on a hard surface over a period of six minutes. The patients are allowed to stop and rest during the test and resume walking when they feel comfortable to do so (Crapo et al. 2002). The 6MWT provides valid and important information regarding an individual’s functional capacity (Du et al. 2009) in activities of daily living (Guyatt et al. 1985). The duration of the walk was initially 12 minutes, but studies have demonstrated that a 3-minute walk test and the 6MWT are as good as a 12-minute walk test (Iriberri et al. 2002). The 6MWT can be performed with or without verbal encouragement. The verbal encouragement has a clear impact on the result; however, the reproducibility of the 6MWT with or without encouragement is similar (Crapo et al. 2002). This indicates that administration of the test should be rigorously standardised within studies to ensure that no bias will occur due to different methods (Guyatt et al. 1985). In patients with severe CHF, the 6MWT provides prognostic information on morbidity and mortality, reflecting physical function aspect on health-related quality of life in measuring impairment (Du et al. 2009). Studies of cardiac patients have shown that reliability of the 6MWT is high (Gayda et al. 2004, Hamilton & Haennel 2000), regarded as a reliable measurement of functional capacity (Du et al. 2009) and useful when evaluating the response to an exercise intervention (Dickstein et al. 2008).

Patient-specific functional scale

The Patient-Specific Functional Scale (PSFS) is a standardised instrument based on the individuals’ self-rated obstacles for activity. The patients identified activities difficult to manage due to current trouble and the severity was rated on a visual numeric rating scale 0-10. The PSFS is a valid and reliable instrument in patients with mechanical low back pain (Stratford et al. 1995), but it has not to my knowledge previously been tested in a population with CHF.
**Disability rating index**

The Disability Rating Index (DRI) questionnaire reflects the participants’ opinion of his/her disability as well as their actual capacity. The DRI is a questionnaire covering 12 items concerning physical function. The 12 items are divided into three sections: common basic activities of daily life, more demanding daily physical activities and work-related or more vigorous activities. The DRI makes it possible to calibrate the instrument individually and this is regarded as good with respect to the wide range of physical baseline capacities in the CHF population. DRI covers different activities that represent gross movement or static physical stress and reflect the function of the spine, legs and arms. The participants mark on a 100 mm visual analogue scale (VAS) in accordance to his/her own presumed ability to perform daily physical activities in question. To perform activities without difficulty is labelled 0 and not being able to perform the activity at all is labelled 100. The use of VAS allows the participant to indicate small alterations in disability. Tests show significant differences between diseases as well as gender and age. The reliability is high and in terms of validity DRI can discriminate between conditions with different expected disabilities into disability categories: none, low, mild-to-moderate and serious (Salén et al. 1994). Cronbach’s alpha in the present study was 0.90. The DRI measures the participants’ opinion of disability, as well as actual capacity. DRI has never been used in explorative or intervention studies in the field of CHF, but was considered to give valuable information of the presumed ability to perform physical activities of daily life.

**Health-related quality of life**

**Short form -36**

See Study I, page 40.

**Minnesota living with heart failure questionnaire**

The Minnesota Living with Heart Failure Questionnaire (MLHFQ) is a disease specific health-related quality of life instrument for use in clinical trials and clinical practice in patients with CHF. It consists of 21 items and is designed to measure the participants’ perceptions of the effects of CHF in
daily life during the last month. Symptoms, morbidity, everyday activities, relationships and depression are listed according to how much each prevents the participant from living as they want, and the patients themselves determine the relative importance of the various impediments to their life (Rector & Cohn 1992, Rector et al. 1987). The scales range from 0 to 5 and the total score can vary from 0 to 105 where a low score indicates better health-related quality of life. Two subscales are identified, a physical dimension and an emotional dimension. The physical dimension includes eight items and the emotional dimension includes five items. The remaining eight items are not grouped and provide a comprehensive assessment (Rector & Cohn 1992). Cronbach’s alpha was 0.88 in the total scale of the MLHFQ, 0.89 in the physical subscale and 0.74 in the emotional subscale. MLHFQ has been tested in an elderly population with good result and is recommended for both research and clinical use. The MLHFQ score is highly correlated with the patients’ overall rating of impact of CHF preventing the patients to do what they want in daily life (Rector et al. 1987). MLHFQ adequately reflects change over time in health status and even has the capacity to discriminate between different magnitudes of the change in patients’ health-related quality of life (Garin et al. 2009). A study on elderly patients with CHF in Sweden (Franzén et al. 2006) shows that the Swedish version of MLHFQ is both valid and reliable.

**Euroqol- 5D-VAS**

EuroQol-5D-VAS (EQ5D-VAS) is a measure of generic self-perceived health status. A visual analogue scale (VAS), obtains a self-rating of the overall health of the participant (Brooks 1996). The scale is anchored at zero, which is the worst imaginable health state, and reaches to 100 that is the best imaginable health state. Validity, reliability and responsiveness for EQ5D-VAS have been tested in different populations with satisfying results (Hurst et al. 1997, Brooks et al. 1991). EQ-5D is frequently used in many clinical areas (Rabin & deCharro 2001) among those CHF (Austin et al. 2009).
**Hospital anxiety and depression scale**

The purpose of The Hospital Anxiety and Depression Scale (HADS) is to identify caseness of anxiety disorders and depression among patients in non-psychiatric hospital clinics. In order to prevent influence from somatic disorders on the scores, as well as symptoms relating to serious mental disorders, all symptoms of anxiety or depression relating also to physical disorders, such as dizziness, headaches, insomnia, and fatigue are excluded (Zigmond & Snaith 1983). HADS focuses on relatively mild degrees of disorder and items are selected in order to distinguish between anxiety and depression. The depression scale is built on the concept of anhedonia and five of seven items refer to loss of pleasure. The anxiety scale refers to fear and panic (three items) and generalised anxiety (four items). HADS is a questionnaire that performs well in screening for separate dimensions of anxiety and depression. The anxiety as well as depression scale range from 0-21 and lower scores indicate lower levels of symptoms of anxiety or depression. Various cutting-points have been quoted where Zigmond & Snaith (1983) proposed that 8-10 on each scale represents possible cases and 11 and more as definitive cases. Bjelland et al. (2002) reports that 8-9 in both of the scales represents the optimal cut-point. HADS is considered to have high reliability (Roberts et al. 2001) and validity (Clarke et al. 1993). Cronbach’s alpha in the anxiety scale in the present study was 0.89 and in the depression scale 0.6. The HADS total score seems to show higher correlations with anxiety or depression criterion measures than the subscales do (McDowell 2006). HADS has newly been used in the field of CHF (Jolly 2009).

**Data collection**

Patients were asked to complete questionnaires and perform physical tests at the primary care setting. Data were collected at baseline and after 3, 6 and 12 months.
Data analysis

The statistical analyses were performed in SPSS version 17.0 (SPSS Inc., Chicago, IL, USA). To characterise the study population, descriptive statistics were used. For statistical evaluation, non-parametric tests, Mann-Whitney, were used in data on ordinal scale and not normally distributed data on ratio scale. Student’s t-test was used in normally distributed data on ratio scale. A \( p \) value <0.05 was considered statistically significant.

In the thesis a comparison was made of health-related quality of life measured by SF-36 with age and gender matched norm populations for the intervention and control. The norm data was obtained from the Healthcare Research Unit, Institute of Internal Medicine, Sahlgrenska University Hospital, Gothenburg University, Gothenburg, Sweden responsible for the validation of the Swedish version of SF-36.
Methodological considerations

Qualitative and quantitative research reflect different views of the nature of the world, the ontology, and how it is organised and classified, the epistemology, which require different criteria in evaluating the quality of the research (Ballinger 2004). Quantitative research is done in a sequential manner where changes of the data collection process after the start of the study may threaten the validity of the findings, whereas qualitative research is a process of discovery and the research process is iterative rather than sequential. The research process of qualitative research is systematic and rigorous, however, not rigid (Forman et al. 2008). Trustworthiness in research is reached when the researcher is able to demonstrate rigour, i.e. the process and relevance, i.e. the end product (Finlay 2006).

Triangulation

Triangulation can be done with regard to data, investigators, theoretical ground, methodology (Denzin 1978), but also with regard to the interdisciplinary approach (Burns & Groves 2005). Data triangulation means collecting data from multiple sources, but with the same foci (Burns & Groves 2005). Different methods of collecting data i.e. data triangulation was used in the thesis since collection consisted of both instruments and physical tests which gives broad information (Study I and IV), as well as in-depth interviews (Study II and III) that sheds light on the experiences from physical limitation in the patient from both a patient and spouse perspective.

Investigator triangulation means that two or more investigators with different research training backgrounds are part of the study and examine the same phenomenon (Mitchell 1986). In nursing research it is common to use both quantitative and qualitative approaches and the co-workers were trained in both. However, there were co-workers more oriented to the quantitative approach, whereas others were more oriented in the qualitative approach.
The theoretical triangulation aims to develop competing hypotheses based on different theoretical perspectives and is tested using the same set of data (Denzin & Lincoln 1994). The presence of cardiac nurses, cardiac nurses with large knowledge from CHF (Study I-III) and a physiotherapist (Study IV) contributed to a broader perspective on the phenomenon explored. The presence of a physiotherapist (Study IV) illuminates a different theoretical approach to the gathered data of physical capacity compared to nurses. However, competing hypotheses are not explicitly formulated in this thesis.

In the context of primary care different theoretical perspectives are present due to different professions in the team; however, it is important to keep the holistic approach. Nursing research is one way to facilitate this since the research conducted by nurses is considered to overlap methodologically with several other disciplines (Risjord et al. 2001).

The methodological triangulation consists of either the within-method or between-method. Each chosen research method is supposed to complement the other and needs to be selected according to relevance to the studied phenomenon. In Study IV the within-method triangulation was done by using different physical tests and questionnaires (Burns & Grove 2005). The between-method is used when methods from quantitative and qualitative research are used in the same study (Mitchell 1986). An attempt of this is done in the discussion of the thesis.

Interdisciplinary triangulation handles the need to lift the research up from, in the discourse where it is done, the dominant ways to see the world (Denzin & Lincoln 1994). The domain of nursing encompasses the wide range of human response to illness and health and emotional, motivational, psychological and social facets of illness (Risjord et al. 2001) implying that the discourse is rather broad. However, in this thesis a cardiac nurse with or without large knowledge in CHF and a physiotherapist has been present which to some extent make interdisciplinary triangulation possible.

**External validity and transferability**

External validity covers under what conditions and with what types of subjects the same result can be expected to occur (LoBiondo-Wood & Haber 2010). Threats of external validity are too big differences in for example time, setting, persons and places. Primary care in Sweden is different in
The theoretical triangulation aims to develop competing hypotheses based on different theoretical perspectives and is tested using the same set of data (Denzin & Lincoln 1994). The presence of cardiac nurses, cardiac nurses with large knowledge from CHF (Study I-III) and a physiotherapist (Study IV) contributed to a broader perspective on the phenomenon explored. The presence of a physiotherapist (Study IV) illuminates a different theoretical approach to the gathered data of physical capacity compared to nurses. However, competing hypotheses are not explicitly formulated in this thesis.

In the context of primary care different theoretical perspectives are present due to different professions in the team; however, it is important to keep the holistic approach. Nursing research is one way to facilitate this since the research conducted by nurses is considered to overlap methodologically with several other disciplines (Risjord et al. 2001).

The methodological triangulation consists of either the within-method or between-method. Each chosen research method is supposed to complement the other and needs to be selected according to relevance to the studied phenomenon. In Study IV the within-method triangulation was done by using different physical tests and questionnaires (Burns & Grove 2005). The between-method is used when methods from quantitative and qualitative research are used in the same study (Mitchell 1986). An attempt of this is done in the discussion of the thesis.

Interdisciplinary triangulation handles the need to lift the research up from, in the discourse where it is done, the dominant ways to see the world (Denzin & Lincoln 1994). The domain of nursing encompasses the wide range of human response to illness and health and emotional, motivational, psychological and social facets of illness (Risjord et al. 2001) implying that the discourse is rather broad. However, in this thesis a cardiac nurse with or without large knowledge in CHF and a physiotherapist has been present which to some extent make interdisciplinary triangulation possible.

External validity and transferability cover under what conditions and with what types of subjects the same result can be expected to occur (LoBiondo-Wood & Haber 2010). Threats of external validity are too big differences in for example time, setting, persons and places. Primary care in Sweden is different in comparison to many other countries; however, a description of the organisation of primary care is done in order to help the reader to understand the professions included. The inclusion and exclusion criteria influence to what extent it is possible to generalise the result. In Study I and IV the inclusion of elderly patients with higher co-morbidity guarantees a more true and representational sample of the real CHF population. The difficulties to include the amount of patients calculated in the power analysis in Study IV must be mentioned. The difficulties arrived, not due to lack of interest in the patients, but rather difficulties to identify and organise the exercise in primary care centres as well as identify controls. Even though no limiting inclusion criteria or exclusion criteria present there were rather few patients meeting inclusion criteria which might have to do with that only patients with systolic CHF were included in the study. Throughout the whole thesis the unequal sex distribution could have confounded the analysis and could negatively influence the possibility to generalise the result, but age and gender matched norms in Study I and IV make comparison and interpretations possible. The risk that only the “healthy” patients with CHF participate in a study since the others do not have the strength must not be neglected, however difficult to handle. Also, in qualitative research the possibility of an “elite bias” has been pointed out meaning that those who are willing to be participants are the most articulate and accessible (Sandelowski 1986). Although qualitative findings cannot be generalised in the same way as quantitative findings, the findings can be generalised across similar contexts (Creswell & Plano-Clark 2006), called transferability. By choosing participants with different experience the possibility for a variety of perspectives increases and the choice of participants, carefully sampled in accordance with inclusion criteria, intends to bring variation of the understanding of the phenomenon. It might have been more different conceptions if there were more men in Study III and women in Study II; however, the outcome space was rich indicating various descriptions. The majority of female spouses are seen earlier in studies (Luttik 2009). Transferability of results requires that the research is presented both detailed and lucid, giving the reader the possibility to evaluate if data is applicable in other settings (Lincoln & Guba 1985). In this thesis a description of the culture and context, selection and participant characteristics, data collection and analysis process aims to illuminate transferability in Study II and III.
Objectivity and confirmability

Objectivity refers to the use of facts without distortion by personal feelings or bias (LoBiondo-Wood & Haber 2010) and by using standardised instruments in Study I and IV with clear instructions objectivity is promoted. However, in Study I patients and spouses answered the questionnaires at their homes. A nurse was present when patients answered their questionnaires, but not when spouses answered their questionnaire. Even though the couple was asked not to discuss the answers this cannot be assured. Further, there was no healthcare professional to answer possible questions. The objectivity or neutrality of the data is called confirmability in qualitative research (Polit & Beck 2010) concerning that interpretations of the findings are clearly derived from the material and that the researcher understands the things as they show themselves. Possible preconceptions have been under careful consideration in all analysis sessions to remain impartial and the result has constantly been questioned to be sure that it came from the interviews. The two supervisors who are familiar with the area of CHF and in the phenomenographic approach have been additional evaluators in the analysis process to ensure an unbiased analysis process. The positive effect of pre-understanding can be a better understanding of the respondents’ views. By using quotations the interpretations of the text are elucidated. The unequal sex distribution in Study II and III could have confounded the analysis since it is well known that physical restrictions are experienced as most burdensome for men with CHF, whereas women seem to experience a lower overall quality of life than men (Strömberg & Mårtensson 2003); however, the outcome space was rich and included various descriptions.

Internal validity and credibility

Internal validity refers to whether observed changes are attributed due to the intervention and not to other possible causes, i.e. the degree in which an independent variable is truly influencing the dependent variable (LoBiondo-Wood & Haber 2010, Polit & Beck 2010). Healthcare research is a human activity and results are affected by human interactions involved and there is
always a risk, needed to be remembered, that pressure in the research context can lead to a post test difference not directly caused by the treatment. A decision was made to have all of the intervention in one county council. The reason of this was the risk of bias in terms of contamination between primary care centres. However, objective physical tests in the intervention must be considered to be stable measurements. Further, most of the questionnaires and tests have been used in the area of CHF and by using standardised and validated instruments, internal validity was reached. The generic and disease specific nature of instruments might make comparison possible between different studies and populations (Hays 2005). In Study IV there were a wide range of physical tests and questionnaires; however, carefully planned not to interrupt each other. Patients started with half of the questionnaires, did physical tests of the upper body, continued with the rest of the questionnaires and ended with the 6MWT. Checking for background characteristics leads to a higher representativeness to the population studied and baseline characteristics showed no differences between exercise or intervention group, except for the use of aldosterone antagonist and beta blockers. In qualitative research the confidence in truth of data and true interpretation of data is labelled credibility, but the use of validated instruments is not applicable since the researcher is the data collecting instrument (Polit & Beck 2010). Credibility also refers to how well the sampling of data and the analysis process focus on the research question. Qualitative researchers need to balance when forming research questions. The research question needs to have adequate focus to allow readers at the end of the study to make a judgement with regards to the degree to which the research question has been answered, but at the same time the research question needs not be too focused to avoid imposing ready made variables and restrict potential variables emerging from the study (Mantzoukas 2008). In Study II and III semi-structured interviews were used to gather data. Initial interview questions were developed with supervisors with knowledge in the area of CHF and the methodological approach in order to make sure that the questions were appropriate due to the research question. Interview as a method of sampling itself was used to gain insights about the phenomena studied which might give different follow-up questions. Different ways to conceive the physical limitation in the patient emerged and new insights were gained which could be considered a quality criterion. In
phenomenographic analysis the data are categorised and not the patients, meaning that one participant can reflect conceptions that are opposite of each other.

Reliability and dependability

Reliability refers to what extent results are consistent over time and if the results from a study can be reproduced with a similar methodology. By using well-recognised instruments with proven reliability the reliability of quantitative research is captured. A threat to reliability is loss of data due to drop-outs. In the intervention group approximately 20%-25%-25% did not perform the follow-ups at 3-6-12 months. In the control group the numbers were 3%-10%-10% respectively. The design in Study I and IV did not allow analysis of drop-outs which must be considered a limitation. See Figure 5 for internal and external drop-outs in Study IV. One way to ensure rigour in qualitative research, i.e. dependability, is to follow previous steps described as developed by previous scholars (Nelson 2008). A rigorous qualitative analysis requires a systematic approach to examine the data in which multiple stages of analysis are typically represented. In the qualitative studies the analysis process followed the seven steps described by Dahlgren & Fallsberg (1991) which indemnify the dependability of data. By following these steps, it was assured that nothing was overlooked and that the results of the studies were consistent, as well as ensuring dependability in these studies.
Figure 5. Flow chart describing how patients with CHF were included and followed up in the study.
Ethical considerations

This thesis was guided by international research-ethical principles outlined in the Declaration of Helsinki (WMA 2000, Northern Nurses Federation 2003, Peter 2006) and approval was obtained from The Regional Ethical Review Board. However, even with approval from an Ethical Review Board, the ethical responsibility falls on the researcher (Johnson 2007).

Respect for autonomy

Avoiding the risk of causing emotional or psychological problems because of exposure in the interviews or questionnaires has been considered in all studies. In the interview studies open and broad questions were used which gave the participants the possibility to run the depth of the interview topic. All participants fulfilling the inclusion criteria received oral and written information about the nature and aim of the study before accepting to participate. All were informed that participation was voluntary and that they could withdraw consent without providing reason for withdrawal at any time prior to the analysis starting without affecting treatment in them or in their loved one. In the studies where spouses were participants (I and III) the patients had authorised spouse participation. No dependency between the researcher and the respondents was considered to exist as the researcher was not involved in the care of the patient.

Non-maleficence

In all studies the researcher must ensure that the research is not more intrusive than necessary. Two studies included interviews with patients (II) or spouses (III). The risk of interviews is to cause emotional or psychological problems because of exposure of a problem in life, sometimes not reflected prior to the interview, which was considered in the studies. Interviews with patients and spouses are of a sensitive nature, including
issues concerning how the illness affects their life and relation to the loved one which was why interviews were accomplished while showing great respect, caution and sensitivity towards patients and spouses. It is my experience that respondents found it important to tell about their situation. In Study IV, medical safety in the intervention group, since this type of care was not standard in this high age, it was taken under careful consideration. Physical exercise in patients with CHF has been shown to be safe and risks even in a higher age were considered small. Two studies (I and IV) included questionnaires which can be tiresome for old, physically impaired patients; however, in Study IV there was no time limit at each session making it possible to take a break if feeling strained. Extra time was given with each respondent in Study II-IV to take care of questions, emotions and psychological reactions from the participants.

**Beneficence**

The direct benefits to participation in Study I are difficult to see and participation was probably out of altruistic reasons in the participants (Williamson 2007). In Study II and III the benefits could be that the participants were allowed to talk about their life situation. All participants that were asked to participate in the interview studies (II, III) accepted participation and many expressed it positive to have had the opportunity to talk about their life situation. When setting up an intervention study the hypothesis must be to do good for patients. In Study IV ordinary treatment was complemented by physical exercise that was hypothesised beneficial in the patients since it has been proved positive in younger patients with CHF in hospital settings. The participants in the control group in Study IV did not gain the hypothesised beneficial treatment. On the other hand, no usual treatment was withdrawn, i.e. patients received normal care.

**The principle of justice**

In Study IV the patients in the control group were not cared for in the same way as those in the intervention group who received standard care and physical exercise. All other care was unchanged. To be fair, all patients in a
study should have the same possibility to participate in the intervention however it was not possible to randomise patients in Study IV due to inconvenience to have intervention at all county councils. In the interview studies (II, III) a strategic sample was done i.e. participants were asked to participate from the perspective that they were different from the other participants and thereby could contribute with variations in the conceptions of the phenomenon. Spouses were only contacted if patients had given their approval which might risk bias in the selection of participants; however, no patient refused participation of the spouse.
Summary of findings

Depression and health-related quality of life in elderly couples (Study I)

Depression

There was no difference between patient and spouses regarding depression as reflected in SDS scores. Patients’ depressive symptoms increased with higher NYHA-class, more impaired mental and physical functioning and more depressive symptoms of the spouse. Patients’ mental and physical functioning accounted for 50% of the adjusted variance in patients’ depression. Spouses’ depressive symptoms increased with higher age of the patient, more impaired mental health and depression in the patient as well as more impaired mental and physical health of the spouse. The mental and physical health of the spouse accounted for 50% of the adjusted variance in spouses’ depression.

Health-related quality of life

Patients with CHF and their spouses experienced different levels of health-related quality of life regarding the physical component of SF-36 where patients experienced significantly worse physical functioning (p=0.008) but not regarding the mental component. In three domains of physical functioning patients experienced significantly lower health-related quality of life; physical functioning (p=0.002), role physical (p=0.044) and general health (p=0.021). In the mental component only the domain of social function differed between patients and spouses with patients having lower health-related quality of life (p=0.031). Also, patients with CHF experienced different levels of health-related quality of life than age and gender matched norms. Patients with CHF experienced worse health-related quality of life in the domains of physical function (p=<0.001), role physical (p=<0.05), general health (p=<0.001),
social function (p=<0.05) and physical component scale (p=<0.01). Spouses had no significant differences when compared to norms Figure 6.

The physical function in the patients as in SF-36 scores improved with better mental health, lower NYHA-class and less depressive symptoms. NYHA-class and depression accounted for 57% of the adjusted variance of patients’ physical functioning. Patients’ mental health was positively related to patients’ physical function and spouses’ mental health and inversely related to NYHA-class and depression in patient and spouse. Patients’ depression and mental health of the spouse accounted for 47% of the adjusted variance in patients’ mental health. Spouses’ mental health was positively related to the mental health of the patient and inversely related to spouses’ depression. Patients’ mental health and spouses’ depression accounted for 36% of the adjusted variance in spouses’ mental health.
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Figure 6. Differences between patients and spouses and age and gender matched norms for patients and spouses.
PCS = Physical component scale, PF = Physical functioning, RP = Role physical, BP = Bodily pain, GH = General health, VT = Vitality, SF = Social functioning, RE = Role emotional, MH = Mental health, MCS = Mental component health.
Norms-p = Patient norms, Norms-s = Spouse norms
† p=<0.05, ‡ p=<0.001
Patients’ experiences of physical limitations in daily life activities (Study II)

A variety of aspects pertaining to physical limitations in activities of daily life was perceived. The referential aspects were: Need of finding practical solutions in daily life, Having realistic expectations about the future, Not believing in one’s own ability and Losing one’s social role in daily life.

In Need of finding practical solutions in daily life, the patients focused on how life had to be changed and that other ways of performing activities of daily life had to be invented. This aspect concerned the patients’ willingness to change focus and how they experienced their changed physical functioning and need of support.

Having realistic expectations about the future was characterised by the belief that, due to increasing age, the future itself would be marked by a change in physical functioning. The patients had an incentive to maintain functions and activities in order to maintain or even increase their capacity in daily life.

Not believing in one’s own ability included the perception of having no opportunity whatsoever to improve one’s ability to perform the activities of daily life. Inability to trust in their own physical capacity along with the experience of limitations in daily life made them cease to attempt to improve their ability to perform activities of daily life. There were perceptions of undesired passivity in terms of physical activities and daily life as well as an undefined fear of straining themselves or performing activities that could endanger their health in addition to uncertainty about the future. This made them limit their activities of daily life.

Losing one’s social role in daily life. The patients described losing their social network as well as their position in society because of their limited physical capacity. A lack of important issues, mental as well as physical, occurred when they lost the physical capacity to perform activities of daily life. The mental part was described as an inability to maintain their concentration long enough to perform what is expected in daily life. Their role as a member of a group or family changed in a negative way.
Patients' experiences of physical limitations in daily life activities (Study II)

A variety of aspects pertaining to physical limitations in activities of daily life was perceived. The referential aspects were:

- Need of finding practical solutions in daily life
  - Focus on how patients had to act and think in different ways in order to manage activities of daily life. Aspects derived: Demanding to change the character of activities, needing to continuously plan the activities of daily life and needing support in order to manage activities of daily life.

- Having realistic expectations about the future
  - Focus on the patients’ expectations of their future life. Aspects derived: Assuming a need for change in daily life, striving to maintain the quality of daily life and continuously making progress in daily life.

- Not believing in one’s own ability
  - Focus on the perception of being unable to influence physical activities of daily life. Aspects derived: Failing to realise their own physical capacity and fear preventing them from performing the activities in daily life

- Losing one’s social role in daily life
  - Focus on the emptiness of work tasks and a lack of social context. Aspects derived: Clear lack of important content in daily life and being unable to manage important activities in daily life.

Table 3. The aspects of physical limitations in patients suffering from CHF.

<table>
<thead>
<tr>
<th>Referential aspects</th>
<th>Structural aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need of finding practical solutions in daily life</td>
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</tr>
<tr>
<td>Having realistic expectations about the future</td>
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<td>Not believing in one’s own ability</td>
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</tr>
<tr>
<td>Losing one’s social role in daily life</td>
<td>Focus on the emptiness of work tasks and a lack of social context. Aspects derived: Clear lack of important content in daily life and being unable to manage important activities in daily life.</td>
</tr>
</tbody>
</table>
Spouses’ experiences of impact on daily life regarding physical limitations in the loved one (Study III)

The spouses perceived a variety of aspects pertaining to the physical limitations in the loved one with CHF and the implication this had on their daily life. The referential aspects were: Losing self-containment, Missing communality, Accommodating to the situation and Finding satisfaction in life.

Losing self-containment comprised restriction in own experiences due to more physical limitations in the loved one. No plans could be made since it was never sure that the loved one could manage the physical strain. Along with loss of activities, there was continuous worry for the loved one. Balancing the life of the loved one had become an important task. Overload in daily life and situations where the spouses own health status had worsened due to the life situation had emerged.

Missing communality was characterised by loneliness since the loved one did not have their former physical strength. Spouses missed the daily life experiences with the loved one and missed the person the loved one used to be. Not being seen and having their needs go unnoticed by people around them was a double loneliness. Spouses were not given recognition for their own needs due to physical limitations in the loved one and were not seen as the resource they wanted to be.

Accommodating to the situation was characterised by the future being viewed with fear as well by the statement “this is the life we have, and this is it”. Thus they took increasing responsibility for activities in daily life left undone by the loved one. Accepting the life situation and seeing change as natural had occurred and a responsibility to keep up the mood had been accepted.

Finding satisfaction in daily life meant that the spouses had what was needed in daily life but also that they perceived the need to find new activities to do on their own or to slightly change their own existing activities. To be together was important and prioritised and spouses had positive thoughts about the future and the possibilities the future held.
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- **Missing communality**: Missing communality was characterised by loneliness since the loved one did not have their former physical strength. Spouses missed the daily life experiences with the loved one and missed the person the loved one used to be. Not being seen and having their needs go unnoticed by people around them was a double loneliness. Spouses were not given recognition for their own needs due to physical limitations in the loved one and were not seen as the resource they wanted to be.

- **Accommodating to the situation**: Accommodating to the situation was characterised by the future being viewed with fear as well by the statement “this is the life we have, and this is it”. Thus they took increasing responsibility for activities in daily life left undone by the loved one. Accepting the life situation and seeing change as natural had occurred and a responsibility to keep up the mood had been accepted.

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<table>
<thead>
<tr>
<th>Referential aspects</th>
<th>Structural aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Losing self-containment</strong></td>
<td>Focusing on the limitations the spouses experience due to physical limitations in the loved one. Aspects deriving: Balancing the life of the loved one, being overloaded, living with worries, needing support to manage practical situations, inability to plan, loss of what is not doable and sacrificing due to guilt.</td>
</tr>
<tr>
<td><strong>Missing communality</strong></td>
<td>Focusing on the loss of fruitful relationship and common experiences. Aspects deriving: Lack of intimacy with the loved one, loss of the loved one, not being paid attention to and lacking mutual experiences.</td>
</tr>
<tr>
<td><strong>Accommodating to the situation</strong></td>
<td>Focusing on seeing change as a part of life and changed roles in the couple came natural. Aspects deriving: Keeping the mood, accepting change in life, being the prime mover in the couple, taking more responsibility in daily life and taking one day at the time.</td>
</tr>
<tr>
<td><strong>Finding satisfaction in daily life</strong></td>
<td>Focusing on that the good parts in life and positive thoughts about the future. Aspects deriving: Identifying personal space, being contented with life, living with positive thoughts about the future and prioritising collaboration.</td>
</tr>
</tbody>
</table>
Effects of a physical exercise programme in primary care regarding physical capacity and health-related quality of life in daily life activities (Study IV)

At baseline there were no significant differences between groups regarding demographics, physical tests and questionnaires, Table 5 and 6. However, there were significantly more patients treated with aldosterone antagonists and beta blockers in the control group at baseline, Table 5.

Physical capacity
Exercise significantly improved muscle function in the upper body compared to the control group at 3, 6 and 12 months except for shoulder flexion right at 12 months (Shoulder abduction p=0.006, p=0.048, p=0.029; Shoulder flexion right p=0.002, p=0.032, p=0.585; Shoulder flexion left p=0.000, p=0.046, p=0.004, respectively), Figure 7. Also 6MWT improved at 3 months (p=0.013), Figure 8. PSFS or DRI showed no significant changes between the groups.

Health-related quality of life
In SF-36 a significant improvement was seen in general health and physical component scale in the intervention group at 3 months (p=0.048 and p=0.026, respectively) compared to the control group. The MLWHF physical scores improved at 3 months (p=0.008) and the EQ5D-VAS was improved significantly at 3 months (p=0.016) and 12 months (p=0.034) compared to the control group, Figure 8. HAD did not significantly change between groups.
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Table 5. Clinical characteristics of participants in study IV.

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of participants</strong></td>
<td>n=28</td>
<td>n=31</td>
<td>0.472</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td><strong>NYHA-class</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>13 (46)</td>
<td>17 (55)</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>7 (25)</td>
<td>14 (45)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>8 (29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Aetiology</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischemic heart disease</td>
<td>10 (36)</td>
<td>13 (42)</td>
<td>0.625</td>
</tr>
<tr>
<td>Heart Infarction</td>
<td>7 (25)</td>
<td>10 (32)</td>
<td>0.539</td>
</tr>
<tr>
<td>Hypertonia</td>
<td>6 (21)</td>
<td>10 (32)</td>
<td>0.350</td>
</tr>
<tr>
<td>Diabetes</td>
<td>8 (29)</td>
<td>4 (13)</td>
<td>0.135</td>
</tr>
<tr>
<td>Cardiomyopathy, dilated</td>
<td>1 (4)</td>
<td>5 (16)</td>
<td>0.111</td>
</tr>
<tr>
<td>Primary valvular disorder</td>
<td>3 (11)</td>
<td>5 (16)</td>
<td>0.544</td>
</tr>
<tr>
<td>Unknown</td>
<td>6 (21)</td>
<td>5 (16)</td>
<td>0.602</td>
</tr>
<tr>
<td><strong>Pharmacological treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACE inhibitor</td>
<td>17 (61)</td>
<td>19 (61)</td>
<td>0.964</td>
</tr>
<tr>
<td>Digoxin</td>
<td>3 (11)</td>
<td>9 (29)</td>
<td>0.081</td>
</tr>
<tr>
<td>Diuretics</td>
<td>23 (82)</td>
<td>23 (74)</td>
<td>0.462</td>
</tr>
<tr>
<td>Aldosterone antagonist</td>
<td>2 (7)</td>
<td>10 (32)</td>
<td>0.020</td>
</tr>
<tr>
<td>Warfarin</td>
<td>8 (29)</td>
<td>18 (58)</td>
<td>0.086</td>
</tr>
<tr>
<td>Beta blocker</td>
<td>21 (75)</td>
<td>29 (94)</td>
<td>0.048</td>
</tr>
<tr>
<td>Long time nitrogene</td>
<td>3 (11)</td>
<td>3 (10)</td>
<td>0.895</td>
</tr>
<tr>
<td>Acetylsalicylsyra</td>
<td>14 (50)</td>
<td>8 (26)</td>
<td>0.055</td>
</tr>
<tr>
<td>A2 inhibitor</td>
<td>9 (32)</td>
<td>12 (39)</td>
<td>0.530</td>
</tr>
</tbody>
</table>

Table 6. Physical tests and questionnaires at baseline. Mean and standard deviation in the SF-36 dimensions of intervention and control with age and gender matched norms.

<table>
<thead>
<tr>
<th>Physical capacity and health-related quality of life</th>
<th>IN</th>
<th>Intervention</th>
<th>Control</th>
<th>CN</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical capacity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-minute walk test</td>
<td>388.9 (51.5)</td>
<td>380.8 (100.3)</td>
<td>0.112</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shoulder abduction</td>
<td>79.3 (53.3)</td>
<td>85.9 (31.5)</td>
<td>0.712</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shoulder flexion right</td>
<td>21.4 (7.8)</td>
<td>28.6 (18.9)</td>
<td>0.148</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shoulder flexion left</td>
<td>19.3 (7.6)</td>
<td>28.4 (18.9)</td>
<td>0.597</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSFS</td>
<td>4.2 (1.9)</td>
<td>4.2 (1.7)</td>
<td>0.982</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRI</td>
<td>35.4 (21.2)</td>
<td>35.8 (17.7)</td>
<td>0.873</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health-related quality of life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SF-36, PF</td>
<td>60.1</td>
<td>64.6 (21.8)</td>
<td>60.3 (21.2)</td>
<td>66</td>
<td>0.699</td>
</tr>
<tr>
<td>SF-36, RP</td>
<td>45</td>
<td>54.5 (42)</td>
<td>54.8 (46.7)</td>
<td>62</td>
<td>0.841</td>
</tr>
<tr>
<td>SF-36, BP</td>
<td>58.2</td>
<td>73.5 (28.9)</td>
<td>76.1 (27.9)</td>
<td>70.8</td>
<td>0.795</td>
</tr>
<tr>
<td>SF-36, GH</td>
<td>62.1</td>
<td>59.1 (22.7)</td>
<td>60.7 (17.9)</td>
<td>64.6</td>
<td>0.829</td>
</tr>
<tr>
<td>SF-36, VT</td>
<td>59.6</td>
<td>59.8 (23.7)</td>
<td>59.2 (18.9)</td>
<td>61.8</td>
<td>0.943</td>
</tr>
<tr>
<td>SF-36, SF</td>
<td>78.5</td>
<td>85.7 (19.5)</td>
<td>80.6 (22.3)</td>
<td>85.9</td>
<td>0.521</td>
</tr>
<tr>
<td>SF-36, RE</td>
<td>75</td>
<td>70.2 (37.8)</td>
<td>53.8 (44.5)</td>
<td>69.1</td>
<td>0.182</td>
</tr>
<tr>
<td>SF-36, MH</td>
<td>75.1</td>
<td>81.4 (17.9)</td>
<td>79.2 (16.5)</td>
<td>82.9</td>
<td>0.302</td>
</tr>
<tr>
<td>SF-36, PCS</td>
<td>38.5</td>
<td>39.9 (11.1)</td>
<td>40.9 (9.8)</td>
<td>43.2</td>
<td>0.872</td>
</tr>
<tr>
<td>SF-36, MCS</td>
<td>54</td>
<td>50.5 (10.8)</td>
<td>47.1 (10)</td>
<td>51.3</td>
<td>0.132</td>
</tr>
<tr>
<td>MLHFQ, total</td>
<td>22.4</td>
<td>24 (17.1)</td>
<td>24 (17.1)</td>
<td></td>
<td>0.982</td>
</tr>
<tr>
<td>MLHFQ, physical</td>
<td>10.6</td>
<td>10.7 (17.3)</td>
<td>10.7 (17.3)</td>
<td></td>
<td>0.815</td>
</tr>
<tr>
<td>MLHFQ, emotional</td>
<td>3.7</td>
<td>4.6 (4.1)</td>
<td>4.6 (4.1)</td>
<td></td>
<td>0.521</td>
</tr>
<tr>
<td>EQ5D-VAS</td>
<td>62.7</td>
<td>67.3 (17.3)</td>
<td>67.3 (17.3)</td>
<td></td>
<td>0.245</td>
</tr>
<tr>
<td>HAD, anxiety</td>
<td>3.1</td>
<td>3.5 (4.3)</td>
<td>4 (3.2)</td>
<td></td>
<td>0.579</td>
</tr>
<tr>
<td>HAD, depression</td>
<td>3.2</td>
<td>4 (3.2)</td>
<td>3.2 (1.8)</td>
<td></td>
<td>0.751</td>
</tr>
</tbody>
</table>

IN= intervention norms, CN= control norms
Table 6. Physical tests and questionnaires at baseline. Mean and standard deviation in the SF-36 dimensions of intervention and control with age and gender matched norms.

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<thead>
<tr>
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<th>CN p-value</th>
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<td>388.9 (51.5)</td>
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</tr>
<tr>
<td>DRI</td>
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<td>35.8 (17.7)</td>
<td>0.873</td>
</tr>
</tbody>
</table>

| Health-related quality of life                     | SF-36, PF       | 60.3 (21.2) | 66.0 (69) |
|                                                    | SF-36, RP       | 54.8 (46.7) | 62.0 (84) |
|                                                    | SF-36, BP       | 76.1 (27.9) | 70.8 (70) |
|                                                    | SF-36, GH       | 60.7 (17.9) | 64.6 (64) |
|                                                    | SF-36, VT       | 59.2 (18.9) | 61.8 (61) |
|                                                    | SF-36, SF       | 80.6 (22.3) | 85.9 (86) |
|                                                    | SF-36, RE       | 53.8 (44.5) | 69.1 (69) |
|                                                    | SF-36, MH       | 79.2 (16.5) | 82.9 (83) |
|                                                    | SF-36, PCS      | 40.9 (9.8)  | 43.2 (43) |
|                                                    | SF-36, MCS      | 47.1 (10)   | 51.3 (51) |
| MLHFQ, total                                       | 24 (17.1)       | 22.4 (15.5) | 0.982      |
| MLHFQ, physical                                    | 10.7 (17.3)     | 10.6 (8)    | 0.815      |
| MLHFQ, emotional                                   | 4.6 (4.1)       | 3.7 (3.4)   | 0.521      |
| EQ5D-VAS                                           | 67.3 (17.3)     | 62.7 (25.3) | 0.245      |
| HAD, anxiety                                       | 3.5 (4.3)       | 3.1 (2.6)   | 0.579      |
| HAD, depression                                    | 4.0 (3.2)       | 3.2 (1.8)   | 0.751      |

IN= intervention norms, CN= control norms

Figure 7. The average difference (Δ%), between intervention and control group in physical fitness. † p=<0.05 ‡ p=<0.01
Figure 8. The average difference ($\Delta\%$), between intervention and control group in 6MWT and EQ5D-VAS. † $p<0.05$
Discussion

Spouses and patients described many difficulties in daily life activities regarding physical capacity and physical limitations in the patient. Patients experienced the physical component as most affecting health-related quality of life (Study I) and activities of daily life were negatively affected in various ways due to physical limitation (Study II). Spouses described difficulties in daily life activities from the physical limitation in the loved one (Study III) and further it was proved that it is possible to conduct an exercise programme in primary care with positive effects on physical fitness and to some extent health-related quality of life (Study IV).

In Study II conceptions of inability to trust in physical capacity in daily life due to the physical deterioration was described. Also, patients experienced that they had no opportunity to influence the physical capacity whatsoever and thereby they did not even try to improve it. This together with low levels of health-related quality of life in the domain of physical function (Study I) imply a considerable limitation in daily life. The findings are in line with a study where usual activities in daily life are problematic in three quarters and mobility problems in two thirds of patients with CHF compared to less than one fifth of a population sample (Calvert et al. 2005). Even though exercise is an established part of the non-pharmacological treatment of patients with CHF (Dickstein et al. 2008) the treatment plan in this elderly population seldom includes exercise and especially not in primary care. Establishing or re-establishing the patients’ self-confidence in his/her physical capacity in both ordinary activities of daily life and exercise is an important task for nurses and other healthcare professionals in the care of patients with CHF in order to promote a rich life. Elderly people most frequently cite high age or poor health as the main barrier to physical activity (Shutzer & Graves 2004) and lay people think that exertion ought to be avoided when having CHF (Remme et al. 2005). This reasoning is devastating in CHF and the lack of
exercise as a natural part of the treatment plan leaves the patient and spouse without guidance and support. This could lead to, despite best intentions, a viscous circle of underperformance and inactivity in the patient, further, leading to the strain of the spouse in the activities of daily life increasing unnecessary. An initial period of exercise in primary care might help the elderly patients and their spouses to learn the benefits and safety of an appropriate level of physical activity and exercise in order to inspire or to be inspired to activity and exercise rather than to limit it.

The exercise intervention (Study IV) showed positive results in physical capacity in the upper body during the whole intervention period. This was an important finding since many of the daily activities patients experienced as a problem (Study II) was due to limited capacity in the upper body. Moreover, many activities require more arm work than leg work (Fletcher et al. 1996) implying that the described improvement gives valuable possibilities to increase daily activities and perform those with greater efficiency. Patients (Study II) also described walking as a difficult activity in life depending on strain when walking, but also on the unpredictable, sudden urge for rest. Further, patients described slowed speed and shortened distance since CHF occurred. Within the couple one activity considered as a loss from the spouses’ point of view (Study III) was just taking walks together. The 6MWT (Study IV) significantly improved in the exercise group compared to the control group at 3 months. A positive outcome was persistent in the exercise group over the whole intervention period however not significant, Figure 8, with a mean distance of 18-30 meters in the different follow-ups. The improvement in distance walked is in line with two studies (Jónsdóttir et al. 2006, Corvera-Tindel et al. 2004), whereas Dracup and co-workers (2007) did not identify an improvement. An improvement in walked distance in 6MWT of 20 meter is considered to be the minimum clinically important change in elderly people (Perera et al. 2006). The increased distance not only indicates the possibility to walk farther, it also indicates raised speed. Through higher speed the possibilities to keep up former activities in the patient and spouse pair is increased, probably an important ingredient in the life of the couple. The increased distance of 6MWT together with gained physical capacity in the upper body can be a clue to the accurate performance of daily life activities. This ought to be beneficial within the
couple as a whole since patients could perform more activities wished for and the strain on the spouse may diminish. Daily activities, measured by accelerometry, are shown to be significantly higher in an exercise group (Witham et al. 2008); however, there seems to be a discrepancy between the capacity of a patient and the actual performance (van den Berg-Emons et al. 2005). This must be taken under consideration from nurses along with other healthcare professionals in the caring of the patient in order to promote activities of daily life. Chronic illness can create barriers to physical performance (Brink et al. 2009) and healthcare professionals need to regularly ask the patients and spouses about actual performance and exercise trying to spur the couple to more activities. Existing barriers of activities of daily life need to be illuminated in order to overcome these.

Significant differences in health-related quality of life between patients and spouses were present (Study I) and even though the physical component of SF-36 affected health-related quality of life most, social function additionally was rated worse in patients than spouses and patient norms. Patients are shown to be frustrated with role failure and negative emotions (Bosworth et al. 2004) and experience themselves as a burden to others (Ekman et al. 2000). These negative features need to be acknowledged and discussed in the care of the patient in order to strengthen the physical as well as the psychosocial part of life, but also to raise awareness of the problems. Even though there were positive results from the exercise intervention in physical capacity there was no significant and stable improvement in health-related quality of life as in SF-36 or MLHFQ scores (Study IV). The neutral result from the exercise programme in health-related quality of life is in contrary to one study (Oka et al. 2000), but in line with others (Dracup et al. 2007, Jónsdóttir et al. 2006). However, meta-analysis of exercise intervention showed a positive effect on health-related quality of life (van Tol et al. 2006). Lack of significant improvement in MLHFQ has earlier been described (Brubaker et al. 2009) and according to those researchers a possible explanation was that the participants had good scores (39.9 points) indicating high perceived health-related quality of life and in Study IV the participants had even better scores in MLHFQ (22.4 points). The varying results in health-related quality of life could be explained by the different content and intensity in the exercise programmes, but probably also by
personal factors. If patients do not perceive an expected increase in health-related quality of life from an exercise programme there is a need to explain and discuss the lack of results with the patient and spouse, but highlight the positive effects of physical capacity, its importance in daily life and spur the patient to continue exercise. EQ5D-VAS showed a positive outcome at 3 and 12 months in the intervention group, even though it was a small sample. EQ5D-VAS is a comprehensive measure accounting for the whole life situation (Brooks 1996) with EQ5D-VAS being earlier shown to be significantly impaired in patients with CHF (Calvert et al. 2005). Hence, EQ5D-VAS may be a useful indicator of the impact of complex comorbidity problems in contrary to detailed questionnaires where not all items are experienced as of importance in elderly patients with CHF. HAD scores did not improve from the exercise intervention (Study IV); however, the scores were very low at baseline indicating almost no symptoms of anxiety or depression. The low rate of depressive symptoms is somewhat surprising since depression is rather usual in CHF (Rutledge 2006) even though low levels of anxiety and depression previously have been shown in an exercise intervention in an elderly population with CHF (Witham et al. 2008). The reason for low depressive symptoms at baseline in Study IV can only be speculated upon and one explanation could be that a patient who chose to participate in an exercise study might not be as depressed as those who chose non-participation. Further, there was a discrepancy between levels of depression in Study I and IV which could be predominantly explained with the use of different questionnaires, but also with that SDS has several questions involving somatic components, i.e. the perceived decrease in health-related quality of life in the physical domains of SF-36 might have influenced the SDS scores negatively.

Isolation had occurred in both patients (Study II) and spouses (Study III). In patients (Study II) the isolation was experienced as losing a role in daily life both in society, but also in family and social gatherings with friends which had become a smaller part than wished for. Both leaving the home to visit someone, but also to invite guests were difficult. The experience of isolation in patients is earlier described (Bosworth et al. 2004) and nurses need to support the patients to identify possible solutions and ways to avoid this. For example, patients can identify the best times, from their point of view, of the
day to visit others, but also realise that the willingness to take a little rest when visiting others might make a big difference in the possibilities of taking part in the social life. Spouses (Study III) experienced a twofold isolation with negative implications in daily life. One way like patients, from family, friends and society since the loved one no longer could take part in that sort of life, but also in a more limiting way because the loved one needed the spouses help at home. This led to experiences of loss of self-containment in life when taking care of the loved one, earlier seen in a study from Pressler and co-workers (2009). The world outside the home seems important to facilitate breathing holes in spouses (Study III) and it is earlier shown that employed spouses perceive higher well-being (Saunders 2010) and better health (Borg & Hallberg 2006). This is an important knowledge for both patients and spouses, but also for nurses and other healthcare professionals about those elderly spouses who no longer perform work outside the homes.

Even more difficult to understand for spouses was the isolation they experienced in the contact with the loved one (Study III). The loved one had changed in personality and developed other traits which spouses were not used to and this affected their relationship. Spouses sometimes had to remind themselves how the loved one used to be and who they married. Spouses did not understand why the loved one no longer “let the spouse in” and a difficulty to communicate and a loss of feeling akin had become a part of life. The sexual part of life was perceived as decreased due to physical limitations in the loved one and carried negative impact in spouses’ lives. Patients have earlier described decreased sexual activity due to the condition (Calvert et al. 2005, Scott 2000) and sexual activities were considered as rather physically demanding by the spouses and the decrease was not logically difficult to understand. Even worse was that cuddling also had decreased, which was considered as even a greater loss and loneliness in the spouse. Healthcare professionals must be perceptive in the narratives of patients and spouses to empower the couple to handle the situation in a prosperous way. It is shown that nurses feel responsible to discuss sexuality with patients; however, the issue is not usually discussed with patients in the daily work (Jaarsma et al. 2010).
Spouses (Study III) experienced both physical and mental strain in daily life due to the physical limitation in the loved one. However, the strain was not necessarily perceived as only negative, but rather was the lack of understanding and support from surroundings, for example family and friends, perceived as troublesome (Study III), earlier seen in Mårtensson et al. (2001). The lack of knowledge in lay people is large where only 4% can identify symptoms of CHF and further, almost 40% think that CHF is a normal consequence of getting older (Remme et al. 2005). Given these gaps in knowledge, it is not difficult to understand the lack of proper support from family and friends. The lack of support was also perceived in relation to healthcare professionals. A study of informal caregivers showed that spouses had support in 25% of the cases, but support was wished for in a further 10%. The support wished for was someone to talk to about caregiving advice, nursing help service or home-help service (Borg & Hallberg 2006). This implies that it is of greatest importance that CHF follow-up of patients with CHF also includes spouses since these needs of help are a normal part of work in nurses. Further, home-help service could make breathing holes possible for the spouse. With home-help service not everything in taking care of the home and to some extent the responsibility of the loved one is not only relying on the spouse. A key component to an effective CHF service is regular assessment and review of the need of the carer (Boyd et al. 2009) which favourably can be facilitated in primary care. However, in order to deliver the at the same time broad and specialised support needed in the course of the syndrome nurses and healthcare professionals in primary care must gain further knowledge in the topic of CHF. Faith in healthcare professionals (Clark et al. 2009) and satisfaction with received care (Schnell et al. 2006) are determinants of self-care and healthcare professionals need to be aware of the influence of the syndrome in daily life in patients with CHF and spouses to be able to meet their needs.

High levels of support in a close relationship have been found to improve health-related quality of life (Chung et al 2009), self-care management (Sayers et al. 2008, Grady & Halvey 2006, Schnell et al. 2006) and survival (Grady & Halvey 2006, Rohrbaugh et al. 2006) indicating that spouses play an important role in the life of patients with CHF especially since it could be assumed that patients with spouses are more likely to adhere to life style
changes. Accordingly, spouses need be taken care of in order to have the
capacity to be supportive to the loved one, but also to manage their own
lives. Also, it is important to have in mind that over a six month period, even
when patients’ health improved the physical health of the spouse decreased
(Rohrbaugh et al. 2009) implying the absolute need to include spouses in the
CHF care and also see the implications the deterioration of the physical
capacity in the patients has on the spouse.

Long term follow-up in patients with CHF is in the majority of cases
managed in primary care (Vilaseca 2008); however, structured CHF care is
not an integrated part of primary care in most cases (Mårtensson et al. 2009).
This is an important limitation since the structured healthcare for these
patients probably leads to better information and advice about the fluctuating
and deteriorating condition which in turn enhances the competence of living
a good life, performing necessary and doable activities of daily life and
proper self-care. Further, patients and spouses valued a key healthcare
professional and a supportive, continuing relationship with that healthcare
professional who could offer personalised information and promote self-care
(Boyd et al. 2009). Since the number of patients with CHF is increasing the
demands on primary care have increased (Agvall et al. 2005) and patients
with CHF have to be taken care of in primary care for many reasons. The
number of patients with CHF in society makes it impossible to take care of
all patients and spouses in secondary care and another reason, even more
important from the patients’ point of view, is a logistic problem. When
patients are getting older, transportation becomes more troublesome and a
visit at the hospital may cost more physical and mental energy than a visit at
the local primary care centre located in the near surrounding of patients’
homes. This energy could be better used to perform and withhold self-care
and activities in daily life. Secondary care has a strong tradition in dividing
wards between different organs and there is a risk that the whole patient and
co-morbidities are not taken care of properly in different settings. The
follow-up of elderly patients with CHF should include a physical,
behavioural, medical, psychological and social factor which makes primary
care favourable for the follow-up since the primary care has a holistic
approach. In line with the holistic approach it is necessary to recognise the
patients and spouses as experts on their own lives. However, a
misunderstanding within the couple of the true grounds of symptoms sometimes is present. Poor knowledge of CHF is present in both patients and spouses even with presence of severe symptoms and the couple tends to explain symptoms of CHF with other illnesses or diseases (Clark et al. 2009).

Elderly patients are often keen to be actively involved in health-promoting activities and self-care behaviours because they prefer to be independent and reliant (Cameron et al. 2009). Independence also comprises the ability to manage daily life activities at a level the patient and spouse both find reasonable. The unpredictable syndrome makes a wide variability of health-related quality of life in different patients even if they are similar in the clinical measurements of CHF and it is necessary to identify that particular patient’s concerns, facilitate communication and guide clinical decision-making (Calvert et al. 2005).

The exercise programme (Study IV) was conducted with healthcare professionals already present as a normal staff in most primary care centres in Sweden, i.e. physiotherapists since it is necessary to be able to incorporate the treatment in ordinary or almost ordinary activity of the primary care centre. Positive effects from intervention comprising exercise seem to be persistent over time and a five year follow-up after a six month intervention showed that almost two thirds continued with some form of exercise (Austin 2009) and better exercise habits were established in the intervention group (Austin et al. 2008). When an intervention with only education on the topic exercise was provided the perceived benefits of exercise decreased (Smeulders et al. 2009) indicating that the practice of exercise is of benefit.
Comprehensive understanding

Primary care has a crucial role to play in older patients with CHF and their spouses. The holistic approach conducted in primary care is favourable in this elderly population with often high co-morbidity. Further, secondary care does not have the possibility to conduct the follow-up in all elderly patients with CHF and is not always the best suited in the long run. In Sweden, the well developed primary care has the opportunity to take care of patients with CHF and it is necessary to incorporate structured CHF follow-up in the ordinary work. However, the professional knowledge must be improved in primary care about the many parts of the CHF syndrome and its implications in daily life of patients and spouses. The physical limitations in the patient have a tremendous impact in the daily life activities of the whole couple and different expectations of the course of the limitations are present. The knowledge in patients and spouses regarding physical activity is scarce and to establish or re-establish the self-confidence in physical capacity is an important issue and nurses along with other healthcare professionals have a responsibility to supply the amount of information needed. Exercise in these elderly patients with CHF can also be provided and prescribed from primary care. A physiotherapist in primary care can with an exercise programme help the patient to exercise in primary care centres and even at patients’ homes. The knowledge about the large need of self-care must rise among nurses and other healthcare professionals in primary care, and from them to patients and spouses. Nurses also need to strengthen self-care in the patient and encourage non-pharmacological treatment in general, but also within physical function and exercise. Self-care includes monitoring symptoms, but also the ability to decide what to do depending on the actual status of the day, a task where spouses are in the highest degree a part of. Spouses must be considered as important in the lives of the patient, but at the same time nurses and healthcare professionals need to remember that spouses often are negatively affected by the course of the syndrome in the loved one and sometimes the situation even negatively affects the spouses’ health. Patients and spouses should be considered as experts in their own lives, but must be
further strengthened in knowledge and self-care in CHF in order to have the best possible health-related quality of life. This can be conducted through the multidisciplinary organisation common in primary care, which has excellent opportunities to strengthen the care in elderly patients with CHF and their spouses and primary care must take the responsibility to do so.

Conclusions

♦ Patients have low health-related quality of life in the physical component compared to age and gender matched norms as well as spouses.
♦ Both patients and spouses are limited in daily life activities due to physical limitation in the patient.
♦ Lack of knowledge of CHF in patients and spouses causes unnecessary low levels of activities of daily life.
♦ Performing activities of daily life and exercise in patients with CHF must be informed about and promoted by healthcare professionals.
♦ Spouses need recognition due to their own needs, but also as important to the course of syndrome in the patient.
♦ It is possible and effective to the physical fitness to prescribe exercise in elderly patients with CHF in primary care and in their homes.
♦ Health-related quality of life is negatively affected when having CHF and it is essential to strengthen the possibilities of performing activities of daily life in the elderly couple, preferably done by nurses and other healthcare professionals in primary care.
Conclusions

- Patients have low health-related quality of life in the physical component compared to age and gender matched norms as well as spouses.

- Both patients and spouses are limited in daily life activities due to physical limitation in the patient.

- Lack of knowledge of CHF in patients and spouses causes unnecessary low levels of activities of daily life.

- Performing activities of daily life and exercise in patients with CHF must be informed about and promoted by healthcare professionals.

- Spouses need recognition due to their own needs, but also as important to the course of syndrome in the patient.

- It is possible and effective to the physical fitness to prescribe exercise in elderly patients with CHF in primary care and in their homes.

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Implications

Clinical implications

Primary care requires recognising and taking care of the follow-up of elderly patients with CHF. Patients are struggling with a variety of difficulties in daily life activities which could to a great extent be relieved or explained with help from primary care. The benefits for even elderly patients to exercise imply that this also ought to be a part of the treatment plan in primary care. It was obvious that patients and spouses were not aware of the possibilities to positively influence activities belonging to daily life, indicating deficits regarding knowledge. The implication of this is twofold. Since many patients are diagnosed and treated solely in primary care, the primary care needs to take a large responsibility in caring for patients with CHF and their spouses and organise care in the best way to deliver the knowledge and skills needed. More, spouses need to be seen by the healthcare system due to strain perceived in daily life. The care of patients with CHF ought to be organised in a way that spouses are one part of the care and spouses should also be seen as a resource in physical exercise i.e. to enable and encourage the loved one. Discussing limitations and possibilities of daily life activities must be a normal part of the appointment with the patient and spouse in order to prevent further deterioration, but also to clarify the thoughts patients might have and meet patients and spouses where they are in gathering knowledge of CHF. Education must be provided to nurses and healthcare professionals in primary care in order to gain further professional knowledge in the width of CHF topics since it is unlikely that patients, spouses and community inhabitants have a good understanding if the healthcare professionals do not have sufficient knowledge. This is necessary in order to support pharmacological as well as non-pharmacological treatment, such as exercise advice along with advice regarding lifestyle to strengthen self-care in the couple. Also, knowledge of CHF and its implications on daily life activities, but also the importance of self-care and exercise even when having this condition must be communicated in the community to avoid false assumptions about risks from physical activity.
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Research implications

Patients’ conceptions regarding participation in an exercise programme in primary care is of importance. Probably both positive and negative experiences are present. Also, spouses are affected when the loved ones are participating in exercise, especially since the fear of exertion has been pointed out which is why their perceptions also must be considered. These different conceptions can be illuminated with a qualitative approach to gather in-depth knowledge.

Patients with systolic CHF were participants in the exercise intervention and future research is also needed in a population with diastolic CHF. An exercise programme conducted in primary care, measuring physical fitness, health-related quality of life and activities of daily life would give evidence whether an exercise intervention is also of benefit in these patients.

An exercise intervention in primary care conducted with participation from both patient and spouse could make spouses more comfortable when the loved one performs activities of daily life and exercise. Perhaps the effect from exercise is larger when the spouse is also a part of the programme since adherence to the exercise might be enhanced. An intervention addressed to clarify these questions could help the couples to manage daily life activities.

In primary care patients with CHF are an increasing part of the practice. Knowledge in the healthcare professionals about the syndrome and its radical changes in daily life of the couple, but also research regarding the healthcare professionals’ attitudes towards patients’ and spouses’ needs must be conducted. The knowledge from such an investigation can constitute a base from where education and training of healthcare professionals in primary care could be built.

An intervention where elderly patients and spouses are educated together in primary care in conformity with management programmes conducted in secondary care could lead to further benefits in the couple and should be evaluated. The evaluation should be both quantitative, in terms of health-related quality of life in both patients and spouses, but also adherence
to non-pharmacological as well as pharmacological treatment and survival and qualitative in terms of perceptions of the couple. At the same time it is important to evaluate the patients’ point of view since they might not always perceive the spousal influence as beneficial.
Swedish summary

Bakgrund

Hjärtsvikt är ett komplext syndrom hos patienten och kännetecknas av såväl symtom som objektiva bevis. Symtom hos patienten är till exempel andnöd vid aktivitet eller vila, extrem trötthet och vätskeansamling runt anklarna medan de objektiva bevisen visar onormal struktur eller funktion i hjärtat. Kranskärlssjukdom är den vanligaste orsaken till utveckling av kronisk hjärtsvikt men även andra orsaker såsom kardiomyopati och fel på hjärtats klaffar förekommer. Förekomsten av hjärtsvikt ökar i befolkningen, delvis beroende av att befolkningen blir allt äldre och att överlevnaden vid koronara händelser förbättrats, men också att träffsäkerheten förbättrats i att förutse koronara händelser genom prevention hos högriskpatienter eller hos dem som redan överlevt en koronar händelse. Förekomsten av kronisk hjärtsvikt beräknas vara 2-3% i befolkningen men ökar kraftigt i 75-årsåldern och i 70-80-årsåldern är det så vanligt som 10-20%. Mortaliteten är hög vid kronisk hjärtsvikt, högre än för mag-, prostata- och blåscancer hos män och bröst-, mag- och äggstockscancer hos kvinnor. En funktionsklassificering, NYHA-klassificering, vid kronisk hjärtsvikt har tagits fram där mild hjärtsvikt används som en beskrivning för de patienter som kan röra sig utan eller med enbart små begränsningar av andnöd och trötthet och svår hjärtsvikt för de patienter som är tydligt begränsade av sina symtom och är i ständigt behov av medicinsk uppsikt. Moderat hjärtsvikt används som beskrivning för den resterande delen av patienter med kronisk hjärtsvikt. Dock är NYHA- klassificering inte alltid relevant vid klinisk vardag då det har visat sig att få läkare i primärvården vet vad NYHA-klassificering är. Dessutom korrelerar inte klinikerns bedömning av NYHA-klass med den bedömnings som patienten gör av sin NYHA-klass. Fysisk funktion är en av de viktigaste komponenterna i livskvalitet och alla människor utför någon form av fysisk aktivitet. Sannolikt har vi alla olika definitioner när vi pratar om fysisk form, fysisk aktivitet och träning. Fysisk form är en rad egenskaper som människor har eller skaffar sig och innefattar

Att vårdna en sjuk anhörig hemma var förr något som ansågs vara normalt men detta ändrades i mitten av 1900-talet då sjukhus blev allt vanligare och vårdpersonal tog över mycket av ansvaret. Nu håller denna trend åter på att vändas mot att patienterna skrivs ut allt tidigare från sjukhus och patienter och make/maka sköter en stor del av vården hemma. Maka/make till kroniskt sjuka patienter upplever sig ofta vara belastade, särskilt när patienten har en dålig prognos. Eftersom kronisk hjärtsvikt är vanligt förekommande hos de äldre i befolkningen innebär det att många personer lever nära dessa
patienter och många anhöriga axlar en vårdande roll. Trots tekniska
teamsteg, förbättrat farmakologisk behandling och patientutbildning så
innebär kronisk hjärtsvikt en successiv försämring. Maka/make upplever
lägre generell hälsa än maka/make till friska personer, oavsett kön. Korrekt
information, även till maka/make kring egenvård vid kronisk hjärtsvikt kan
förbättra både relationens kvalitet men också förmågan till egenvård vid
kronisk hjärtsvikt.

Farmakologisk och icke-farmakologisk behandling har utvecklats mycket de
senaste årtiondena och består av en komplex behandlingsplan med
mediciner, vätskebegränsning, kostråd, symtom monitorering och
träningsråd där egenvård är en del av en framgångsrik behandling av kronisk
hjärtsvikt. Att följa en komplex behandlingsplan påverkar det dagliga livet
för både patient och maka/make och just denna påverkan kan göra
följsamheten till behandling svår.

I Sverige remitteras äldre patienter med kronisk hjärtsvikt oftast till
primärvården för uppföljning. Med tanke på att antalet personer med kronisk
hjärtsvikt ökar så ökar också kraven på primärvården. Hälso-
och sjukvårdslagen anger att ”primärvården ska som en del av den öppna vården
utan avgränsning vad gäller sjukdomar, ålder eller patientgrupper svara för
befolkningens behov av sådan grundläggande medicinsk behandling,
onvårdnad, förebyggande arbete och rehabilitering som inte kräver
sjukhusens medicinska och tekniska resurser eller annan särskild
kompetens”. Primärvården har en holistisk syn och har kunskap om
individen, vars sjukdomar och tillstånd kommer och går, till skillnad från
specialistvården som har en smalare syn på sjukdom och det är patienterna
som kommer och går. Där det finns en väl utvecklad primärvård finns det
goda möjligheter att bedriva koordinerad vård för dessa patienter och
multidisciplinära team är optimala för prevention och behandling av
kroniska tillstånd. Organiserad vård i primärvården för patienter med kronisk
hjärtsvikt är anmärkningsvärt ovanligt med tanke på bevisen för dess
positiva effekt inom den specialiserade vården. Patienter med kronisk
hjärtsvikt ansvarar själv för den största delen av vården och god egenvård
kan signifikant påverka fysisk kapacitet, välmående, symtom, och prognos.
Maka/make har en viktig roll i egenvården eftersom även de känner igen och
tolkar patientens symtom. Behandling vid kronisk hjärtsvikt sker dessutom
ofta med hjälp av en familjemedlem.
Kronisk hjärtsvikt påverkar hälsorelaterad livskvalitet mer än de flesta andra kroniska sjukdomar. Hälsorelaterad livskvalitet är en viktig del att ta hänsyn till vid kronisk hjärtsvikt då det visat sig att patienter är beredda att byta överlevnad mot förbättring i hälsorelaterad livskvalitet. Den fysiska dimensionen av hälsorelaterad livskvalitet är mest påverkat vid kronisk hjärtsvikt, vilket leder till negativ påverkan i det dagliga livet. Även när medicineringen är optimerad så är patienten begränsad av sin fysiska kapacitet och missnöjet med aktiviteter i det dagliga livet är förknippat med försämrad hälsorelaterad livskvalitet. Depression förekommer hos ungefär var femte patient med kronisk hjärtsvikt. Både depression och kronisk hjärtsvikt är associerade med aktivering av det sympatiska systemet vilket påverkar hjärtat negativt. Dessa negativa effekter kan reduceras med träning.

Studiernas syfte och resultat

Huvudsyftet med avhandlingen var att utforska och beskriva parets erfarenheter av patientens fysiska begränsning i det dagliga livets aktiviteter och utvärdera effekten av ett träningsprogram i primärvården vid kronisk hjärtsvikt.

Syftet med delstudie I var att avgöra om äldre patienter med hjärtsvikt och deras make/maka upplever liknande nivåer av hälsorelaterad livskvalitet och depression samt att identifiera faktorer som bidrar till hälsorelaterad livskvalitet i paret. Resultatet visade att patienter och anhöriga upplever skillnader avseende den fysiska komponenten där patienten upplever sämre hälsorelaterad livskvalitet. Fysisk funktion, fysisk rollfunktion och generell hälsa upplevdes alla som sämre av patienterna. Den mentala komponenten skilde sig inte förutom att social funktion skattades lägre hos patienterna. Det fanns inga skillnader mellan patient och make/maka avseende depressionssymptom. Den fysiska funktionen hos patienten var bättre vid bättre mental hälsa, lägre NYHA- klass och mindre depressiva symptom. Patientens mentala hälsa var bättre vid bättre fysisk funktion hos patienten, bättre mental hälsa hos make/maka, lägre NYHA- klass hos patienten samt lägre nivå av depressionssymtom hos make/maka och hos patienten.
I delstudie II var syftet att beskriva hur patienter med kronisk hjärtsvikt uppfattar sin fysiska begränsning i det dagliga livets aktiviteter. Patienternas olika uppfattningar beskrivs i följande aspekter: Behov av att hitta praktiska lösningar i det dagliga livet, det vill säga hur livet tvingats att förändras och att andra sätt att utföra dagliga aktiviteter behövde identifieras. Att ha realistiska förväntningar på framtiden innebar att patienterna uppfattade att livet i sig självt, beroende av ålder, skulle innebära en förändrad fysisk funktion. Att Inte tro på sin egen förmåga innebar uppfattningen att patienten inte trodde sig ha någon som helst förmåga att utföra aktiviteter i det dagliga livet. Förlora sin sociala roll i det dagliga livet medförde att patienten förlorade sitt sociala nätverk och sin plats i samhället och en saknad av viktiga uppgifter uppstod.


Delstudie IV syftade till att fastställa effekten av ett träningsprogram på fysisk aktivitet och hälsorelaterad livskvalitet hos äldre patienter inom primärvården med kronisk hjärtsvikt. Träning påverkade den fysiska kapaciteten signifikant positivt i överkroppen under hela interventionen (3-6-12 månader) samt 6-minuters gångtest vid 3 månader. Hälsorelaterad livskvalitet förbättrades inte entydigt men ett mått på sammantagen livskvalitet (EQ5D-VAS) förbättrades signifikant vid 3 och 12 månader.
Diskussion

Patienter och make/maka beskrev många svårigheter i det dagliga livets aktiviteter avseende fysisk förmåga och fysisk begränsning hos patienten. Patienterna uppfattade mest påverkan på hälsorelaterad livskvalitet inom den fysiska komponenten (Studie I) och det dagliga livets aktiviteter var negativt påverkade på en rad olika sätt på grund av fysisk begränsning (Studie II). Även make/maka beskrev svårigheter i det dagliga livets aktiviteter som en följd av fysisk begränsning hos patienten (Studie III) och slutligen bevisades det att det är möjligt att genomföra ett träningsprogram i primärvården med positiva effekter på fysisk form och till viss del hälsorelaterad livskvalitet (Studie IV).

Patienterna beskrev uppfattningar av att inte kunna tro på sin fysiska kapacitet i det dagligaivet på grund av fysisk begränsning. De uppfattade dessutom att de inte kunde påverka den fysiska kapaciteten och därmed provade de inte att förbättra sin förmåga. Detta tillsammans med lågt skattad hälsorelaterad livskvalitet i den fysiska komponenten tyder på en avsevärd begränsning i det dagligaivet. Även om träning är en etablerad del av den icke-farmakologiska behandlingen av patienter med kronisk hjärtsvikt så omfattar oftast inte behandlingsplanen hos äldre patienter i primärvården detta. En viktig uppgift för sjuksköterskor och annan hälso- och sjukvårdspersonal är att upprätta eller återupprätta självförtroendet hos patienten avseende den fysiska kapaciteten vad gäller aktiviteter i det dagligaivet men även när det gäller träning. Äldre personer hänvisar ofta till dålig hälsa som en anledning till att inte träna och dessutom så anser lekmän att ansträngning ska undvikas vid kronisk hjärtsvikt, ett resonemang som är förödande för patienter med kronisk hjärtsvikt. En initial period med träning inom primärvården kan hjälpa patient och make/maka att se fördelarna och säkerheten med träning för att på så sätt inspirera till ytterligare aktiviteter. Träningsprogrammet gav positiva effekter avseende fysisk kapacitet i överkroppen under hela interventionsperioden. Eftersom många av de aktiviteter som patienterna uppfattade som problematiska var just relaterade till överkroppen och att det dessutom är så att många aktiviteter kräver mer armarbete än benarbete är detta ett viktigt fynd. Även längden i 6-minuters gångtest ökade signifikant vid 3 månader i den gruppen som tränade. En
positiv utveckling var stabil över hela interventionsperioden men förändringen var inte signifikant vid 6 och 12 månader. Denna förbättring kan sannolikt positivt påverka patientens möjligheter i det dagliga livets aktiviteter. Det är viktigt att fråga patienten hur aktiva de är i det dagliga livet men också identifiera möjliga hinder för aktivitet och träning då det är bevisat att patienter inte alltid presterar så mycket de verkligen har kapacitet till.

Hälsorelaterad livskvalitet, mätt med EQ5D-VAS, visade signifikanta förbättringar i träningsgruppen vid 3 och 12 månader. I övrigt visade träningsinterventionen inga stabila resultat med avseende på hälsorelaterad livskvalitet. Även tidigare studier har visat varierande resultat med förbättring eller ingen påverkan på hälsorelaterad livskvalitet. Anledningarna till detta kan vara många, dels olika intensitet på träningen men också vilken bakgrund det finns till den kroniska hjärtsvikten kan spela roll. I interventionsstudien i denna avhandling uppnåddes inte det antal patienter som var kalkylerat vilket kan vara en anledning till uteblivet resultat. Viktigare är att patienterna redan vid baslinjemätningen hade, enligt ett sjukdomsspecifikt instrument för hälsorelaterad livskvalitet, bra hälsorelaterad livskvalitet vilket också kan vara en förklaring.

gentemot patienten. Patienten hade ibland ändrat sin personlighet och fått andra karaktärsdrag än vad de hade från början vilket påverkade förhållandet och patienten ”släppte inte in” make/maka längre. Den sexuella delen av livet hade minskat på grund av de fysiska begränsningarna hos patienten men ännu värre uppfattades det att mys, kel och närhet hade minskat. Inom sjukvården måste hälso- och sjukvårdspersonal vara medvetna om detta och hjälpa paret med att hantera situationen på bästa sätt.


Långtidsuppföljning av patienter med kronisk hjärtsvikt görs till största delen inom primärvården men det är ovanligt med strukturerad uppföljning för dessa patienter. Det är en brist då just strukturerad uppföljning ofta leder till bättre information och råd kring det varierande men allt mer försämrade tillståndet. Ökad information kan i sin tur leda till ökade möjligheter till att leva ett bra liv och klara av att göra aktiviteter i det dagliga livet samt utföra relevant egenvård. Eftersom antalet patienter med kronisk hjärtsvikt ökar i samhället är det inte möjligt för specialistvården att ta hand om samtliga patienter men även logistiken är en anledning för primärvården att ta hand om dessa äldre patienter. Det är svårare att transportera sig för den äldre delen av befolkningen och det tar allt mer kraft. Den kraften kunde bättre behövas för att hantera det dagliga livets aktiviteter och egenvård. Patienterna är experter på sina liv men missförstånd inom paret avseende de korrekta orsakerna till symtom existerar vilket sjuksköterskor och övrig sjukvårdspersonal inom primärvården måste korrigera. Träningsprogrammet
i primärvården genomfördes av sjukgymnaster. Det är en yrkeskategori som redan idag finns på de flesta vårdbädder vilket stärker primärvärdens möjligheter att tillhandahålla god vård.

Övergripande förståelse

kan ta sig uttryck i en försämrad hälsa. Patienter och anhöriga ska ses som experter på sitt eget liv men kunskapen om kronisk hjärtsvikt måste stärkas för att ha bästa möjliga hälsorelaterad livskvalitet. Detta kan genomföras genom den multidisciplinära organisationen som är vanlig inom primärvården. Primärvården har utmärkta möjligheter att stärka vården av den äldre patienten med kronisk hjärtsvikt och deras make/maka och måste ta detta ansvar.

**Konklusion**

- Patienten har låg hälsorelaterad livskvalitet i den fysiska komponenten jämfört med make/maka samt en köns- och åldersmatchad normpopulation.
- Både patienter och make/maka är begränsade i det dagliga livets aktiviteter på grund av fysisk begränsning hos patienten.
- Bristande kunskap kring kronisk hjärtsvikt hos patienter och anhöriga orsakar onödigt låga nivåer av aktivitet i det dagliga livet.
- Att prestera aktiviteter i det dagliga livet samt att fysiskt träna måste informeras om och främjas av hälso- och sjukvårdspersonal.
- Make/maka måste ses med tanke på egna behov men också som viktiga i utvecklingen av det kroniska hjärtsviktssyndromet hos patienten.
- Det är möjligt och effektivt att förskriva träning till äldre patienter med kronisk hjärtsvikt i primärvården och i patientens hem.
- Hälsorelaterad livskvalitet är negativt påverkad vid kronisk hjärtsvikt och det är nödvändigt att stärka möjligheterna att utföra det dagliga livets aktiviteter hos det äldre paret, vilket med fördel kan göras av sjuksköterskor och annan hälso- och sjukvårdspersonal i primärvården.

**Kliniska implikationer**

Primärvården måste ta hand om uppföljningen av den äldre patienten med kronisk hjärtsvikt. Patienterna kämpar med en rad svårigheter i det dagliga livets aktiviteter som till en stor del skulle kunna förklaras och lindras med hjälp från primärvården. Nyttan för även äldre patienter att träna tyder på att

Forskningsimplikationer

Patientens uppfattningar om deltagande i ett träningsprogram i primärvården är viktigt. Förmodligen finns både positiva och negativa erfarenheter. Även make/maka påverkas när patienten deltar i tränning, särskilt som rädsla för ansträngning har uttryckts vilket gör att även deras uppfattningar bör studeras. Dessa olika uppfattningar kan belysas med en kvalitativ ansats. Patienter med systolisk kronisk hjärtsvikt deltog i träning-
interventionen och framtidiga forskning behövs i en grupp av patienter med diastolisk hjärtsvikt. Ett träningsprogram i primärvården, där fysisk kapacitet, hälsorelaterad livskvalitet och aktiviteter i det dagliga livet mäts skulle ge bevis huruvida träning i primärvården är till nytta även för dessa patienter.

Ett träningsprogram i primärvården där både patient och make/maka deltar kan göra make/maka mer bekväm med att patienten träner samt utför aktiviteter i det dagliga livet. Möjligen är det så att effekten från träning är större när också make/maka deltar i träningen eftersom då följsamheten till träning då ytterligare kan förbättras.

Kunskap hos hälso- och sjukvårdspersonal inom primärvården kring kronisk hjärtsvikt och dess radikala förändring i det dagliga livet hos paret, men också hälso- och sjukvårdspersonalens attityder till patient och make/maka behöver beforskas. Kunskapen från en sådan studie kan ligga till grund för utbildning av hälso- och sjukvårdspersonal i primärvården.

En intervention där äldre patienter och deras make/maka utbildas tillsammans i primärvården, i likhet med utbildning som sker i specialistvården, skulle kunna leda till ytterligare vinster för paret och bör utvärderas. Utvärderingen bör omfatta hälsorelaterad livskvalitet hos både patient och make/maka, följsamhet till icke-farmakologisk behandling samt farmakologisk behandling och överlevnad men också hur paret uppfattar interventionen. På samma gång är det viktigt att utvärdera patientens syn på detta då make/makas påverkan och deltagande kanske inte alltid uppfattas som fördelaktigt.

Acknowledgements

There are several people I would like to thank. Without your help and support it would never have been possible to complete this thesis:

♦ All the participants of the studies. Thank you for so willingly sharing your knowledge and experiences. I hope and intend that my results will benefit other patients with CHF and their spouses in the future.

♦ My supervisor Jan Mårtensson. It is not possible to have a better supervisor! Thank you for believing in me, the fruitful and sometimes intense discussions we had, your support and guidance in the world of research, your engagement and good advice. Also, thanks for all the laughs!

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♦ Professor Anna Strömberg. Thank you for invaluable comments on my manuscripts!

♦ M.D. Bengt-Göran Hansson and Bodil Ljungberg. Thank you for your help with all cardiopulmonary exercise tests. I am happy that the retired staff still is available to help doctoral students!

♦ Anna Jacobsson and Kent-Ove Alfredsson. Thank you for identifying patients and spouses!

♦ Kirsti Moberg and Gunilla Fritzon. Thank you for all help with echocardiography in the participants!
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♦ PhD Åsa Cider. Thank you for your guidance in the jungle of physical activity, physical fitness, and exercise. Also, thank you for important comments in Study IV.

♦ Professor Anna Strömberg. Thank you for invaluable comments on my manuscripts!

♦ M.D. Bengt-Göran Hansson and Bodil Ljungberg. Thank you for your help with all cardiopulmonary exercise tests. I am happy that the retired staff still is available to help doctoral students!

♦ Anna Jacobsson and Kent-Ove Alfredsson. Thank you for identifying patients and spouses!

♦ Kirsti Moberg and Gunilla Fritzon. Thank you for all help with echocardiography in the participants!
Carina Hjelm. Thank you for all your help in Linköping!

All engaged physiotherapists in the County Councils of Halmstad, Jönköping and Linköping. Thank you for organising the exercise, conducting all tests in physical capacity and collecting all questionnaires. It could not have been done without you!

All personnel at the hospital library, Länssjukhuset in Halmstad. Thank you for all your help!

Aase Tortsensson. Thank you for my illustrations, both my small “men” but also the spider net!

My children, Alva and Sara. The two of you never let me lose myself in the labyrinth of science, but constantly reminded me of what is important in life. Girls, the work is now finished! You are the best that has ever happened in my life and I love you more than words can ever express!

My beloved husband Lasse. Thank you for being calm when the world was strained, being a dictionary, always believing in me and in every possible way easing my journey. This could not have been done without you and I love you tremendously!

My fantastic parents, Kerstin and Lars. Thank you for raising me to continuously need to know more and always dare to question the answers given. Thank you also for never-ending support and endless love!

My brothers Henrik, Ola and their families. I am privileged and happy to have such a wonderful family!

Anna Jacobsson, my dear friend. The journey got lonely without you but thank you for not giving up on me, all your encouragement and support!

The Leghammar family. Thank you for all support in everyday life, good laughs, delicious wine and skiing!

All my dear friends for fantastic friendship and all kinds of support. I am so lucky to have you all!
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EXERCISE IN PRIMARY CARE CENTRE

<table>
<thead>
<tr>
<th>RPE</th>
<th>TIME/REPETITIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>9-11</td>
<td>5-10 minutes</td>
</tr>
</tbody>
</table>

WARM UP

AEROBIC EXERCISE

- ▲ 12-13  5-10 minutes
- ▼ 15-17  10-15 repetitions x 2

RESISTANCE TRAINING

- ▼ 15-17  10-15 repetitions x 2

Description of exercise intervention provided at the primary care centre. The amount of repetitions and the load in the exercise was individually prescribed, approximately 75% of 1 repetition maximum. RPE =rate of perceived exertion
HOME-BASED EXERCISE

<table>
<thead>
<tr>
<th></th>
<th>RPE</th>
<th>TIME/REPETITIONS</th>
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<tr>
<td>WARM UP</td>
<td>9-11</td>
<td>5-10 minutes</td>
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<tr>
<td>AEROBIC EXERCISE</td>
<td></td>
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<tr>
<td>![Aerobic Exercise Diagram]</td>
<td>15-17</td>
<td>10-15 repetitions x 2</td>
</tr>
<tr>
<td>RESISTANCE TRAINING</td>
<td>15-17</td>
<td>10-15 repetitions x 2</td>
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</tbody>
</table>

Description of exercise intervention provided at the primary care centre. The amount of repetitions and the load in the exercise was individually prescribed, approximately 75% of 1 repetition maximum. RPE = rate of perceived exertion
Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses: a comparative study

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Received 11 December 2003; received in revised form 14 July 2004; accepted 29 July 2004

Available online 17 March 2005

Abstract

Background: Little is known about the factors that influence the health outcome of elderly patients suffering from heart failure or the health of their spouses. The aim of this comparative study was to determine if older patients suffering from heart failure and their spouses experience similar levels of health-related quality of life (HRQOL) and depression. The aim was also to identify those factors that contribute to HRQOL and depression in patient–spouse pairs.

Methods: Data were collected from 47 couples, using the Short Form 36 (SF-36) and Zung Self-rating Depression Scale (SDS) questionnaires.

Results: Patients suffering from heart failure and their spouses differed significantly in their experience of the physical, but not the mental, health-related quality of life, with patients experiencing significantly worse physical functioning. Physical symptoms of heart failure seemed to dominate the experience of the patient and was positively related to mental health and inversely related to the New York Heart Association classification (NYHA class) and patients' depression. Depressive symptoms as reflected in SDS showed no significant difference between patients and spouses. Patients' depression was positively related to high NYHA class, while spouse depression was positively related with higher age of the patient.

Conclusion: Physical symptoms seem to dominate the experience of heart failure.

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Keywords: Depression; Heart failure; Health-related quality of life; Patient–spouse pairs

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Little is known about the factors that affect the health outcome of elderly patients suffering from heart failure and their spouses. It is known that chronic illness in a family member influences all aspects of family life and that the family has a key role in the development of the course and outcome of chronic illness as well as in the way the illness is perceived and experienced by the patient [1].

M3rtensson et al. [2] found that American male patients in their sixties suffering from heart failure were significantly more depressed and had poorer physical functioning compared to their spouses. The present study addresses patients older than 60 years suffering from heart failure and their spouses. Living with heart failure can be stressful because the condition leads to complex demands on patients and their families [3]. Patients suffering from heart failure and their spouses face several difficult issues [2]. Mild to moderate heart failure can have a minor 

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1. Background

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influence, whereas severe heart failure requires major changes in the lives of the couple [4]. Debilitating physical symptoms, frequent hospitalisations, forced retirement, role changes, financial pressure and disruption of the usual sources of social support characterise the course of the disease. All of these changes can lead to significant depression and reduction in quality of life in both patients [5] and spouses [6], which in turn can increase morbidity and mortality [7]. Symptoms experienced by the spouses can be high levels of anxiety, depression, tension, fatigue, sleep and eating disturbances as well as other psychosomatic symptoms [8]. The spouses’ central concern seems to be the patient’s well being [9]. In one of the few studies addressing spouses of patients suffering from heart failure, Karmilovitch [6] found that providing caring for the sick husband was burdensome and stressful. The most burdensome activities, from the Physical Care Scale, were watching the spouse’s condition deteriorate without being able to intervene and not knowing if they would be able to cope with caring for the patient in the future. The most burdensome behaviours, from the Role Alterations Scale, were being unable to participate in social/recreational activities; being unable to share problems and concerns with the partner, and changes in the personality of the partner. Young and Kahana [10] stated that caring for patients suffering from heart disease was similar to caring for terminally ill patients, as both groups tend to suffer from depression, anxiety and other serious mental health problems. Most spouses of cardiac patients ignore their own needs when their loved ones are ill [11]. The spouse’s primary concern is the patient and they may therefore feel guilty about seeking help for themselves, which creates a barrier to receiving emotional support from others [9]. Psychosocial issues have been studied in patients suffering from heart failure as well as their spouses, but only one study has focused on patient–spouse pairs to determine if they experience similar feelings of depression and health-related quality of life (HRQOL) [2]. Heart failure is a growing problem with major clinical importance in the general population with the highest prevalence among the elderly [12]. Therefore, it is of great importance to study this group of patients and their spouses. The aim of this comparative study was to determine if elderly patients suffering from heart failure and their spouses experience similar levels of HRQOL and depression. The aim was also to identify factors that contribute to HRQOL and depression in patient–spouse pairs.

2. Methods

2.1. Design and setting

This study utilised a cross-sectional comparative design and was conducted at primary health care centres situated in two cities in south-eastern Sweden. The Ethical Committee for Human Research at Linköping University, Linköping, Sweden, approved the study.

2.2. Sample and criteria

The inclusion criteria were; diagnosed heart failure based on echocardiography, radiographic evidence of pulmonary congestion or typical symptoms, signs of heart failure and New York Heart Association (NYHA) classes II–IV, aged over 60 years, and resident in the catchment area. Spouses were included if they were living in the same household as the patient. Patients and spouses were excluded if they had dementia or other psychiatric illness expected to affect the study outcome or had difficulties in understanding or reading the Swedish language.

2.3. Instruments

Data on actual health status was obtained through simple questions about mobility, pain/discomfort and self-care. The reliability and the validity of the SF-36 have been established in patients suffering from heart failure [13]. The SF-36 has been translated into Swedish, adjusted to and tested in a Swedish population [14]. The SF-36 comprises 36 multiple-choice questions divided into two dimensions and eight subscales that describe overall health status. The subject is asked to rate each of the 36 items as it applies to him/her. The physical health (PCS) is obtained by combining scores on the following four subscales of the SF-36: The physical functioning subscale (PF), the role physical subscale (RP), the bodily pain subscale (BP) and the general health subscale (GH). The mental health scale (MCS) is also based on four subscales of the SF-36: vitality (VT), social functioning (SF), role emotional (RE) and mental health (MH) [14]. The instrument does not yield a total score.

The Zung Self-rating Depression Scale (SDS) has been designed to provide a quantitative assessment of the subjective experience of depression, and it emphasises somatic and behavioural components (50% of the total score) to a greater extent than most other self-rating depression scales. A translated and back-translated Swedish version was used in the study. The SDS contains 20 items covering affective, psychological and somatic features of depression. Of the 20 items, 10 were worded positively and 10 negatively. The subject is asked to rate each of the 20 items on a Likert scale with values ranging from 1 to 4 to indicate how it applied to him/her. The total raw SDS scores range from 20 to 80. An index for the SDS was used by dividing the sum of the values (raw scores) of the twenty items by the maximum possible score, which equaled 80. The converted SDS scores range from 0.25 to 1.0. Non-depressed individuals typically score less than 0.50, mildly depressed 0.50–0.60, moderately depressed 0.61–0.70, while the score of those with severe depression is generally higher than 0.70 [15]. The scale correlates well with
clinician ratings, DSM-III-R diagnosis of depression, and with Beck Depression Inventory scores [16].

2.4. Procedure

The primary health care centres were screened for patients suffering from heart failure through the Diagnosis Related Groups (DRGs) registry in order to identify those who fulfilled the inclusion criteria. A primary health care nurse visited the patients in their homes and provided both verbal and written information about the study. The patients were asked to complete the questionnaire at home and to give another copy of the questionnaire to their spouse. The completed questionnaires were returned in a stamped addressed envelope. Patients and spouses were informed that participation was voluntary and that they could withdraw from the study at any time. Confidentiality was guaranteed, and it was also emphasised that none of the informants could be identified. They were instructed to complete the questionnaires without discussing their answers with each other.

2.5. Statistical analysis

Descriptive statistics were used to characterise the study population. For statistical evaluation, non-parametric tests were used. The Wilcoxon matched pairs test was used to evaluate the differences in depression and HRQOL, between patients suffering from heart failure and their spouses. Correlations between age, physical and mental health, and depression were evaluated for both patients and spouses, while NYHA class was only assessed in patients. Pearson product-moment correlation coefficients were used for variables that were normally distributed and on an interval scale. Variables that were not normally distributed due to outliers were analysed using Spearman’s rank correlation coefficient. Univariate linear regression was performed with age, PCS, MCS and SDS in patients and spouses and NYHA class in patients as dependent variables, in order to identify which variables could significantly predict depression and HRQOL. The variables that significantly predicted depression and HRQOL were then included in a multivariate stepwise regression analysis to identify which combination of variables provided the most predictive power. A $p$ value $<0.05$ was considered statistically significant.

3. Results

As shown in Table 1, 47 couples participated in the study. Thirty-four of the patients were male and 24 were in NYHA class II and 19 in NYHA class III. The actual health status according to three questions was similar between patients and spouses regarding pain/discomfort and self-care, whereas the patients had more problems in walking about. Patients had a mean age of 78 years while the spouses had a mean age of 75 years.

3.1. Comparison of depression and health related quality of life (HRQOL)

There was no significant difference between patients and spouses regarding depressive symptoms, as reflected in SDS scores ($p=0.115$). Patients had a mean of 0.52 ($\pm0.12$), while spouses had a mean of 0.50 ($\pm0.11$). Using the SDS, 28 patients were identified as having mild to severe depression (20 mild, 4 moderate and 4 severe) and 22 spouses as having mild to severe depression (16 mild, 4 moderate and 2 severe). When patients and spouses were compared using the two dimensions and the eight scales of the SF-36 (Fig. 1), a significant difference was documented in the physical component (PCS) ($p=0.008$). Three aspects of the physical functioning component individually; physical functioning ($p=0.002$), role physical ($p=0.044$), and general health ($p=0.021$). In each case patients experienced significantly lower HRQOL than their spouses. There was no difference between the groups in the mental component (MCS) ($p=0.891$) except for the dimension social functioning ($p=0.031$) with patients experiencing significantly lower HRQOL than their spouses.

| Table 1 Characteristics of the pairs (n=47) consisting of patients suffering from heart failure and their spouses (n=94) |
|---------------------------------|-----------------|
| Gender                         | Patient (n)     |
| Male                           | 34              |
| Female                         | 13              |
| Age in years mean (SD)         | 78 ($\pm5$)     |
| Etiology of HF                 | Ischaemic heart disease 30 |
| Myocardial infarction          | 23              |
| Hypertension                   | 18              |
| Diabetes                       | 9               |
| Valvular heart disease         | 4               |
| Cardiomyopathy                 | 1               |
| NYHA                           |                 |
| Class II                       | 24              |
| Class III                      | 19              |
| Class IV                       | 1               |
| Missing                        | 3               |
| Mobility                       |                 |
| I have no problems in walking about | 18          |
| Pain/Discomfort                |                 |
| I have no pain or discomfort   | 12              |
| I have moderate pain or discomfort | 32          |
| I have extreme pain or discomfort | 3           |
| Self-care                      |                 |
| I have no problems with self-care | 42         |
| I have some problems washing or dressing myself | 4     |
| I am unable to perform my usual activities | 1     |

The Zung Self-rating Depression Scale (SDS) has been used. The SDS contains 20 items to and tested in a Swedish population [14] . The SF-36 comprises 36 multiple-choice questions divided into two physical subscale (PF), the bodily pain subscale (BP) and

$$I have some problems washing or dressing myself 4 \text{ 46}$$

$$I am unable to perform my usual activities 1$$

$$\text{Gender}$$

$$\text{Male}$$

$$\text{Female}$$

$$\text{Age in years mean (SD)}$$

$$\text{Ischaemic heart disease}$$

$$\text{Myocardial infarction}$$

$$\text{Hypertension}$$

$$\text{Diabetes}$$

$$\text{Valvular heart disease}$$

$$\text{Cardiomyopathy}$$

$$\text{NYHA}$$

$$\text{Class II}$$

$$\text{Class III}$$

$$\text{Class IV}$$

$$\text{Missing}$$

$$\text{Mobility}$$

$$\text{Pain/Discomfort}$$

$$\text{Self-care}$$

$$\text{I have no problems with self-care}$$

$$\text{I have some problems washing or dressing myself}$$

$$\text{I am unable to perform my usual activities}$$

$$\text{Patients had a mean age of 78 years while the spouses had a mean age of 75 years.}$$
3.2. Correlates of depression and health related quality of life

In the interpretation of the correlations presented in Table 2, it is important to keep in mind that high scores on the SDS indicate high levels of depressive symptoms, while high SF-36 levels indicate better HRQOL.

3.2.1. Results from Zung Self-rating Depression Scale

Patients’ depression was positively related to high NYHA class and spouses’ depression and inversely related to patients’ mental and physical health (i.e. the patients’ depressive symptoms increased with a higher NYHA class, more impaired mental and physical functioning and more depressive symptoms of the spouse). Patients’ mental and physical functioning accounted for 50% of the adjusted variance in patients’ depression.

Spouses’ depression was positively related to the age of the patient, patients’ depression, and inversely related to patients’ mental health and spouse’s mental and physical health (i.e. the spouse’s depressive symptoms increased with higher age of the patient, more impaired mental health and depression in the patient as well as with more impaired mental and physical health of the spouse). The mental and physical health of the spouse accounted for 50% of the adjusted variance in spouses’ depression.

3.2.2. Results from SF-36

Patients’ physical functioning was positively related to the mental health of the patient and inversely related to NYHA class and patients’ depression (i.e. physical functioning improved with better mental health, lower NYHA class and less depressive symptoms). NYHA class and depression accounted for 57% of the adjusted variance of the patients’ physical functioning.
Patients’ mental health was positively related to patients’ physical functioning and spouses’ mental health and inversely related to NYHA class, and depression in the patient and spouse (i.e. better mental health in the patient with better mental health in the spouse, lower NYHA class, less depression in patient and spouse and better physical functioning in the patient). Patient’s depression and mental health of the spouse accounted for 47% of the adjusted variance in patients’ mental health.

Spouses’ mental health was positively related to the mental health of the patient and inversely related to spouses’ depression. Patients’ mental health and spouses’ depression accounted for 36% of the adjusted variance in spouses’ mental health.

4. Discussion

This study demonstrates that elderly patients suffering from heart failure and their spouses have different perceptions of their physical health, with patients experiencing significantly lower physical health than their spouses. High NYHA class, depression and age were predictors of low physical health in the patients. It should be noted that the levels of physical health of patients, but not of spouses, were significantly lower than the Swedish norm for persons older than 75 years, (with means of physical functioning 59.0, role physical 49.3, bodily pain 63.2, and general health 59.8) (Fig. 1) [14]. Unfortunately, limited data on spouses’ health status and no data on spouses’ medical history were obtained, and therefore we do not know the possible influence these factors might have on the outcome. In a study of spouses caring for individuals suffering from heart failure, Karmilovich [6] found that almost 1/3 of the spouses reported having cardiovascular problems despite their mean age not being higher than 57 years. Other reported health problems were diabetes mellitus (17%), arthritis (12%) and stress related symptoms (10%). Ebbesen et al. [17] found that spouses of cardiac patients suffered from headache, increased blood pressure and non specific chest pain and that their symptoms were so severe that they had consulted a physician. Since spouses in this study were older, it is not surprising that they had health problems of their own. In the present study, there was no significant difference between patients and spouses regarding depressive symptoms. Patients’ depression correlated with high NYHA class, but there was no correlation between spouses’ depression and high NYHA class. These results are in concordance with Rohrbaugh et al. [18], but contrast to Märtensson et al. [2] where the majority of the patients were in NYHA class III and had a mean age of 61 years. Märtensson et al. found that patients were more depressed than their spouses and that there was a correlation between spouses’ depression and high NYHA class. In the present and in Rohrbaugh et al.’s [18] study, the majority of the patients were in NYHA class II. This might explain why they did not feel more depressed than their spouses as well as the fact that no correlation was found between low functional class and spouses’ depression. Märtensson et al. [2] also found that spouses’ depression correlated with lower patient age. In contrast, spouses’ depression in the present study correlated with higher patient age. It seems that the younger wives have difficulties adjusting to the functional impairment in younger partners while, among elderly couples, the oldest experience most difficulties. As one would expect, there was a significant positive relationship between spouses’ and patients’ mental health and depression. This relationship was not seen among younger patient-spouse pairs [2]. Surprisingly, no positive relationship was found between spouses’ mental health and depression and patients’ physical functioning. Older spouses might be better prepared to accept a deterioration in the physical functioning of their husband or wife than personality changes and depression [4,19]. Interestingly, patients and spouses did not report any significant difference in the overall mental component of their HRQOL, a scale that reflects vitality, social functioning, role limitations and mental health. This suggests that the disease has a bearing on the psychological

Table 2

<table>
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<th>9</th>
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</thead>
<tbody>
<tr>
<td>1. Age of patient</td>
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<td>–</td>
<td>–</td>
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<tr>
<td>2. Age of spouse</td>
<td>0.649***</td>
<td>–</td>
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<td>–</td>
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<tr>
<td>3. NYHA class</td>
<td>–0.040</td>
<td>–0.256</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
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<tr>
<td>4. Patient PCS</td>
<td>–0.241</td>
<td>0.054</td>
<td>–0.653**</td>
<td>–</td>
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<td>–</td>
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<tr>
<td>5. Patient MCS</td>
<td>–0.192</td>
<td>0.035</td>
<td>–0.311*</td>
<td>0.294*</td>
<td>–</td>
<td>–</td>
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<tr>
<td>6. Spouse PCS</td>
<td>–0.243</td>
<td>–0.272</td>
<td>0.011</td>
<td>–0.072</td>
<td>0.038</td>
<td>–</td>
<td>–</td>
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<td>–</td>
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<tr>
<td>7. Spouse MCS</td>
<td>–0.239</td>
<td>–0.057</td>
<td>–0.038</td>
<td>0.136</td>
<td>0.311*</td>
<td>0.229</td>
<td>–</td>
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<tr>
<td>8. Patient SDS</td>
<td>0.045</td>
<td>0.011</td>
<td>0.301*</td>
<td>–0.459**</td>
<td>–0.537**</td>
<td>–0.085</td>
<td>–0.227</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>9. Spouse SDS</td>
<td>0.349*</td>
<td>0.265</td>
<td>–0.049</td>
<td>0.018</td>
<td>–0.343*</td>
<td>–0.487**</td>
<td>–0.589**</td>
<td>0.293*</td>
<td>–</td>
</tr>
</tbody>
</table>

NYHA=New York Heart Association functional class; SDS=Zung Self Rating Depression Scale; PCS=Physical Component Summary; MCS=Mental Component Summary.

* p<0.05=–Spearman’s rank correlation coefficient.
** p<0.01=–Spearman’s rank correlation coefficient.
*** p<0.01=–Pearson’s product-moment correlation coefficient.
well being of older married couples equally. Contrary to this result, Rohrbaugh et al. [18] found that younger patients with heart failure (mean=53 years) were generally more distressed than their spouses. Spouses have low priority in health care and there is a risk, especially for older spouses, that they are forgotten in an environment essentially devoted to patient care [4,20]. This is devastating since the spouse appears to suffer as much emotional disturbance as their partner. Although couples are faced with the same issues related to lifestyle changes, physical challenges, and future uncertainties that require a common approach, they also have unique responses that need to be acknowledged and supported by nurses and physicians. Spouses may feel resentment due to the new demands that the illness places on them. British researchers found that female spouses who continued to enjoy their work and leisure activities and who had satisfying marriages were less distressed one year after their partner became ill [18]. In the present study the spouses had a mean age of 75 years, which means that they were past retirement age and thus no longer working outside the home. This could lead to a higher degree of isolation especially since heart failure has been shown to restrict the life situation for both patient and spouse [4]. Patients suffering from heart failure often feel like a burden due to their dependence on others for carrying out daily activities and because they are a source of worry to others [21,22]. Isolation is a major impediment to recovery for both patient and spouse. Limitations of the result are the small sample size and cross-sectional design, which means that no causality could be discerned among the variables. Although the informants were instructed to complete the questionnaires without discussing their answers with each other, there is no guarantee that they adhered to these instructions. The unequal sex distribution in the study could have confounded the analysis since it is well known that physical restrictions are experienced as most bothersome for men with heart failure, whereas women seem to experience a lower overall quality of life than men [23]. Data on education was not obtained and this is also a factor which could have confounded the analysis.

5. Conclusion

A quantitative, comparative study design, based on the SF-36 and SDS questionnaires, was used to determine if elderly patients suffering from heart failure and their spouses experienced similar levels of HRQOL and depression. Forty-seven couples completed the questionnaires. In the SF-36 it was found that the patients’ physical dimension of HRQOL was clearly impaired by heart failure but that the mental QOL showed no significant difference. High NYHA class, depression and age accounted for more than half of the patient’s experience of poor physical health. The fact that couples did not exhibit significantly different mental health suggests that the disease affects the psychological well being of both partners equally. Depressive symptoms as reflected in SDS scores showed no significant difference between patients and spouses. Patients’ depression was positively related to high NYHA class, while spouses’ depression was positively related to higher age of the patient.

6. Implications

The care of patients suffering from heart failure remains a challenge. It is important to inform patients and spouses that they may develop feelings of burden, which can vary in severity. Specialised cardiac nurses can have a great influence upon the level of demands and stress experienced by spouses of patients suffering from heart failure. Patients and spouses have to confront many difficult issues, and a chronic illness in a partner influences all aspects of the relationship. It is important to be honest with the patient and their spouse about the future and deteriorating physical health, the frequent personality changes and reduced life expectancy. Because spouses’ responses to illness influence patients, it is important to design interventions to support spouses. Clinicians need to develop strategies that focus on the individual as well as the couple, aimed at enhancing communication between patients and their spouses. Nurses can encourage spouses to take care of themselves, to talk to others with similar experiences and to join a support group. Since the physical functioning of patients is clearly impaired by heart failure, clinical interventions should be targeted at improving their functional status by encouraging them to engage in physical activity and regular exercise whenever possible. The spouses’ involvement might help the patient to better manage such activities, thus reducing the risk of a further deterioration in their condition. It is important that the spouse be taught ways to support patient choices that lead to increased physical activity, such as simple but concrete guidelines on how to exercise by performing everyday activities. The bulk of the research on spouses of cardiac patients has utilised quantitative approaches with few studies concentrating on the perceptions of spouses following their partners’ illness. Increasingly, overburdened healthcare systems, although sensitive to the patients’ needs, often overlook the spouses’ needs. Further research with a more equal sample of male and female patients is needed to determine gender differences in patient and spouse roles in relation to the influence of the illness and satisfaction with family function. It will however, prove difficult to achieve gender balance in future research, due to the fact that there are fewer female cardiac patients and, in general, females suffering from coronary disease tend to be older as well as widowed at the time of the cardiac event. No instrument can adequately describe the experience of caring for a spouse with an illness such as heart failure, and in-depth interviews may be the most effective way to examine this problem.
References

Patients' experiences of physical limitations in daily life activities when suffering from chronic heart failure: a phenomenographic analysis

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Scand J Caring Sci; 2010

The aim of the study was to describe how patients suffering from chronic heart failure conceived their physical limitations in daily life activities. An explorative and qualitative design with a phenomenographic approach was chosen, a total of 15 patients were interviewed. The findings indicate that participants perceived a variety of structural aspects pertaining to physical limitations in activities of daily life which resulted in four referential aspects.

Need of finding practical solutions in daily life focused on how life had to be changed and other ways of performing activities of daily life had to be invented.

Having realistic expectations about the future was characterised by belief that the future itself would be marked by change in physical functioning, but an incentive to maintain functions and activities ensured good quality of or even increased capacity in daily life.

Not believing in one's own ability included the perception of having no opportunity to improve ability to perform activities of daily life. There were perceptions of undesired passivity, undefined fear of straining themselves or performing activities that could endanger their health in addition to uncertainty about the future. In

Losing one's social role in daily life, participants described losing their social network and their position in society and family because of limited physical capacity. A lack of important issues, mental and physical, occurred when physical capacity was lost. In conclusion, patients suffering from chronic heart failure found new solutions to manage activities in daily life, including willingness to change focus and identify other ways of doing important things. Patients had an incentive to maintain functions and activities to ensure a good quality of and strengthen their physical capacity in daily life. Inability to trust in their physical capacity in combination with experienced limitations in daily life prevented patients from attempting to increase activities.

Keywords: activities of daily life, chronic heart failure, elderly, nursing care, phenomenography, physical limitations.

Submitted 13 March 2009, Accepted 12 January 2010

Background

Chronic heart failure is a common condition among Europe's ageing population. The syndrome occurs at a median age of around 75 (1) and affects 1–3% of the general population and approximately 10% of elderly people (2). The number of people suffering as well as dying from chronic heart failure will increase as a result of improved treatment and survival rates for other cardiovascular diseases (3). Another contributory factor is heightened awareness of heart failure syndrome resulting in more people receiving the diagnosis in combination with the rapidly growing proportion of elderly individuals in the population (4). Chronic heart failure is commonly defined as a pathological state in which an abnormality in cardiac functioning is responsible for failure of the heart to pump blood at a rate commensurate with the requirements of the metabolising tissues (1). The severity of heart failure ranges from no physical limitations whatsoever to major restrictions in daily life, see Fig. 1. Chronic heart failure is a difficult disease to live with and places a great burden on the patient, his/her family and society (2). In a review on the subject of life situation, Yu et al. (5) described chronic...
Patients’ experiences of physical limitations in daily life activities when suffering from chronic heart failure; a phenomenographic analysis

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heart failure as a debilitating and distressing condition leading to many negative physical and psychosocial consequences for older persons. In Friedman’s study (6), impairment of physical functioning was the most striking finding in older adults with chronic heart failure. A study by Pihl et al. (7) revealed that older patients suffering from chronic heart failure had significantly lower levels of physical health based on SF-36 scores than the Swedish norm in a general population of the same age. Other dimensions of the SF-36 did not have the same impact. Elderly patients suffering from chronic heart failure describe such a lack of physical strength and inability to be as efficient and of use to themselves and others as they would wish, which often leads to feelings of uselessness (8). A number of therapies have been shown to improve exercise capacity in older patients with chronic heart failure (9–11), but there is poor correlation between symptoms and the degree of cardiac impairment (12, 13), and the activities of daily life appear to be more difficult to influence (14, 15). This may reflect the fact that the symptoms are subjective, indicating how the patient feels but not necessarily the severity of the disease. The symptoms do not only reflect the physical aspects of chronic heart failure but are associated with the impact on lifestyle, anxiety, depression and patient expectations (16). It has also been shown that the activities of daily life are not only limited by symptoms, as some patients with chronic heart failure perform such activities at a level well below that of their exercise capacity (17). Activities of daily life can be defined as the self-care, communication and mobility skills required for independence in everyday life (18). The ability of older patients to perform such activities is often affected by fatigue (19), shortness of breath (1, 8), concomitant chronic conditions and normal ageing (1). Fatigue is reported as being a common and distressing condition, characterised by feelings of impaired functioning, difficulties, reduced motivation and tiredness, which have a negative impact on the activities of daily life (19). These activities can be restricted by reduced exercise capacity, which has an impact on older patients’ independence, thus patients could become trapped in a vicious circle of inactivity and decreasing functional capacity. In addition to heart failure, a range of personal, environmental and social factors may limit the ability to perform activities (20). Although chronic heart failure primarily affects older patients, little is known about how they perceive the physical limitations in their activities of daily life. To our knowledge, no study has evaluated the different situations in the daily life of elderly patients to gain knowledge of the areas in which they experience problems. Activities of daily life are an important clinical aspect in chronic diseases, especially in the case of frail, older patients in whom prolongation of life may not always be the primary aim of therapy (21). Many patients also experience increased effort and decreased quality in their performance of activities of daily life (22). One goal of health care must be to maximise function in these activities within the specific limits imposed by the disease. It is therefore of major importance to identify the aspects of physical limitation that the patient finds most troublesome to be able to support him/her to take responsibility for his/her self-care. Accordingly, the aim of the study was to describe how patients suffering from chronic heart failure perceived their physical limitations in daily life activities.

### Material and method

#### Design and method description

The study took place in a county council area in the southwest of Sweden. Permission was obtained from the head of the department as well as from the ethics committee. An explorative and qualitative design with a phenomenographic approach was chosen to explore the qualitative variations in the participants’ conceptions of limitations in physical functions of daily life. Phenomenography was developed in the early 1970s in Sweden within the domain of learning but has since spread from the educational context to that of health science research (23). This approach is based on the patient perspective, and its essence is how something is conceived to be. Conceptions are the foundation in the individual decision-making and
how people act. Phenomenography aims to describe the various ways in which people conceive the world in a cognitive way as opposed to how the world really is, resulting in a description of the variations in the way a phenomenon is experienced (24), which has two aspects; structural and referential. The two aspects are connected to each other and appear at the same time when something is experienced. The structural aspect refers to the fact that when people experience something, they discern its parts from the context, the way they are related to each other and the way they relate to the whole. When the whole and the parts and the relationship between them are clarified further degrees of meaning are discerned. The referential aspect is the overall significance attributed to a phenomenon and built up by means of different structural aspects that are part of the whole phenomenon (25).

Participants

The participants comprised 15 patients recruited from a heart failure clinic in a county hospital. The inclusion criteria were heart failure, diagnosed by means of echocardiography and ability to speak and understand the Swedish language. In accordance with the phenomenographic tradition, the participants were strategically selected to obtain variation with regard to sex, age, place of residence, education and New York Heart Association (NYHA)-class (26), see Table 1. Exclusion criteria were other serious physical or mental disorders. The participants were asked to take part in the study by the heart failure nurse after a follow-up visit to the heart failure ward. The heart failure nurse explained the aim of the study verbally and provided each potential participant with written information. The potential participants were contacted 1–2 weeks later, which gave them time to consider whether or not they wanted to take part. They were informed that participation was voluntary, that they could withdraw at any time prior to the start of the analysis and that the interview data would be treated confidentially. The participants, who all agreed to participate, were not dependent on the researchers in any way. Before inclusion, written consent was obtained from all participants.

Data collection

The interviews were conducted by the first author (EP) over a 3-month period. A pilot interview was performed to test the validity of the opening questions, which the author and supervisors (BF, JM) deemed appropriate and minor changes were made in the questions. The pilot interview was included in the data. The participants chose the location for the interviews, 12 of which took place in the participants’ home and three at the hospital. The interviews lasted for up to 40 minutes and were semi-structured to capture how old people suffering from chronic heart failure experience their physical limitations. The opening questions were: ‘What are daily life activities for you?’ and ‘Are there any physical activities in your daily life that you find difficult to manage?’. These were followed by probing questions such as: ‘Can you describe that in more detail?’ and ‘In what way?’. The interviews were audio taped and transcribed verbatim.

Findings

The participants perceived a variety of aspects pertaining to physical limitations in activities of daily life, see Table 2. The referential aspects were: Need of finding practical solutions in daily life, Having realistic expectations about the future, Not believing in one’s own ability and Losing one’s social role in daily life.

In Need of finding practical solutions in daily life, the participants focused on how life had to be changed and that other ways of performing activities of daily life had to be invented. This aspect concerned the participants’ willingness to change focus and how they experienced their changed physical functioning and need of support.

Table 1 Demographic and clinical characteristics of the participants (n = 15)

<table>
<thead>
<tr>
<th>Sex</th>
<th>10/5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>76 years</td>
</tr>
<tr>
<td>Mean age</td>
<td>76 years</td>
</tr>
<tr>
<td>Time between diagnosis and data collection</td>
<td></td>
</tr>
<tr>
<td>0–12 months</td>
<td>8</td>
</tr>
<tr>
<td>&gt;12 months</td>
<td>7</td>
</tr>
<tr>
<td>NYHA-class</td>
<td></td>
</tr>
<tr>
<td>NYHA-class II</td>
<td>3</td>
</tr>
<tr>
<td>NYHA-class III</td>
<td>11</td>
</tr>
<tr>
<td>NYHA-class IV</td>
<td>1</td>
</tr>
<tr>
<td>Civil status</td>
<td></td>
</tr>
<tr>
<td>Co-habiting</td>
<td>9</td>
</tr>
<tr>
<td>Single</td>
<td>6</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Comprehensive school, 9 years</td>
<td>5</td>
</tr>
<tr>
<td>High school, &lt;12 years</td>
<td>3</td>
</tr>
<tr>
<td>University, ≥12 years</td>
<td>7</td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>9</td>
</tr>
<tr>
<td>Semi-urban/rural</td>
<td>6</td>
</tr>
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The structural aspects were: Demanding to change the character of activities: Needing to continuously plan the activities of daily life and Needing support to manage activities of daily life. Demanding to change the character of activities concerned discovering other ways of doing the important things in life to continue as they had performed previously. It also included changing activities slightly or doing them in a different way. The participants described how they identified other methods of carrying out activities and used new ways of managing such situations. There were participants who reported breaking up activities: ‘Now I have to divide it up. // As I see it, in the future I will have to divide

the lawn into sections. Here it is very hilly. // I can’t manage both sections at the same time. I do the slope first and then continue on the other side. I take one section at a time.’

Need to continuously plan the activities of daily life concerned the necessity of planning what they needed, wanted and had to do. Physical limitations led to the need for forward planning to be able to manage all the physical demands of activities of daily life such as shopping and cooking. Forward planning was perceived as both positive and negative and included both social events as well as everyday needs: ‘I plan a lot what to eat, what I need and what I can buy in advance in order to ensure that it stays fresh.’

Needing support to manage activities of daily life was also perceived as both positive and negative as well as something that the participants had to adjust to. In the case of the latter, the participants usually had home help of some kind. There were participants that considered their limited physical capacity and need of support as a burden because they experienced that they inconvenienced the helpers, while others found it natural that friends and family members helped them: ‘There’s a lot that needs to be done. I make a list of things that I can’t manage myself. For example, I can’t carry a whole basket of laundry from the basement. // But my children take care of that when they come home.’

Having realistic expectations about the future was characterised by the belief that, because of increasing age, the future itself would be marked by a change in physical functioning. The participants had an incentive to maintain functions and activities to maintain or even increase their capacity in daily life. Structural aspects were Assuming a need for change in daily life, Striving to maintain the quality of daily life and Continuously making progress in daily life. Assuming a need for change in daily life meant that changes, including the chronic heart failure, were an accepted and expected part of life when getting older. There were participants who accepted the situation more easily than others, who experienced annoyance about their limitations: ‘I have stated that buying a newspaper, one kilometre forth and back, takes maybe an hour. You may stop and rest, it is not

Table 2 The aspects of physical limitations in patients suffering from chronic heart failure

<table>
<thead>
<tr>
<th>Referential aspect</th>
<th>Structural aspect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need of finding practical solutions in daily life</td>
<td>Focus on how patients had to act and think in different ways to manage activities of daily life. Aspects derived: demanding to change the character of activities, needing to continuously plan the activities of daily life and needing support to manage activities of daily life.</td>
</tr>
<tr>
<td>Having realistic expectations about the future</td>
<td>Focus on the participants’ expectations of their future life. Aspects derived: Assuming a need for change in daily life, striving to maintain the quality of daily life and continuously making progress in daily life.</td>
</tr>
<tr>
<td>Not believing in one’s own ability</td>
<td>Focus on the perception of being unable to influence physical activities of daily life. Aspects derived: failing to realise their own physical capacity and fear preventing them from performing the activities in daily life</td>
</tr>
<tr>
<td>Losing one’s social role in daily life</td>
<td>Focus on the emptiness of work tasks and a lack of social context. Aspects derived: clear lack of important content in daily life and being unable to manage important activities in daily life.</td>
</tr>
</tbody>
</table>
much that you can do about it, you can’t go any quicker, you just can’t do it. Then, whatever you want to do it is just an established limitation.’

In the aspect Striving to maintain the quality of daily life, the participants were satisfied with their level of capacity. They were able to perform the activities they wanted and had to do at a satisfactory level. Trying to perform physical activities that they had previously been able to do and discovering that certain functions had been maintained led to satisfaction: ‘Yes, it feels good! I then understood that this physical movement is quite gentle. And you walk and stop and stand still a lot. So there were no problems.’

In Continuously making progress in daily life, the participants described their wish to achieve better physical capacity, to be able to do what they wanted and their satisfaction when the attempted physical activities were performed successfully or even improved over time. Trying new activities and thinking about future possibilities made the participants advance one step further in their ability to carry out the activities of daily life: ‘Now my lactic acid level rises if I climb even a small slope. And I imagine that there is no other way than starting and taking it easy and gradually lowering the tendency towards an increase in lactic acid.’

Not believing in one’s own ability included the perception of having no opportunity whatsoever to improve one’s ability to perform the activities of daily life. Inability to trust in their own physical capacity along with the experience of limitations in daily life made them cease to attempt to improve their ability to perform activities of daily life. There were perceptions of undesired passivity in terms of physical activities and daily life as well as an undefined fear of straining themselves or performing activities that could endanger their health in addition to uncertainty about the future. This made them limit their activities of daily life. Structural aspects were Failing to realise their own physical capacity and Fear preventing them from performing the activities in daily life.

Failing to realise their own physical capacity contained the perception of being unable to influence daily life with regard to their condition and just accepting the situation. The inability to trust in their physical capacity led them to do what they usually did and nothing more. There were also participants who ended up becoming passive: ‘I think that gardening in the spring is a real burden. But I suppose I will manage somehow. It’s no fun when you feel like that. When you sort of can’t... many people are like that - I do this now and it works out fine. I can’t imagine that it will go well if I do it, no.’

‘You sit too much in front of the television and don’t go out enough’.

In the case of Fear preventing them from performing the activities in daily life, the participants described a fear of death as well as a more undefined fear about the future and of reaching their limits. The fear concerned various things such as going on holiday abroad and led to a situation where the participants always had to think of whether they dared perform a specific activity. Suddenly life was no longer endless. The fear of reaching their limit included anxiety about straining themselves or that they could take ill and no one would find them and be able to help: ‘I don’t think I dare to dig or rake and I don’t really know how much I dare to do because of my heart.’

Losing one’s social role in daily life. The participants described losing their social network as well as their position in society because of their limited physical capacity. A lack of important issues, mental as well as physical, occurred when they lost the physical capacity to perform activities of daily life. The mental part was described as an inability to maintain their concentration long enough to perform what is expected in daily life. Their role as a member of a group or family changed in a negative way. The structural aspects were: A clear lack of important content in daily life and Being unable to manage important activities of daily life.

A clear lack of important content in daily life included missing their physical capacity, physical activities and the opportunity for normal bodily movement and work tasks. There was also a mental loss as a result of too few experiences of a social or cultural nature. A life filled with meaning and interesting things to do was reported to be crucial: ‘Sometimes I become sad because I want to do more. At least when I think that I can’t do anything, almost nothing.’

Being unable to manage important activities in daily life comprised the problem of unexpected tiredness or fatigue. Resting and sleeping had become a larger part of their life than they wanted as the physical function had deteriorated. Tasks had to be performed, for example, at home but the participants perceived them as impossible as a result of their lack of initiative or fatigue. It was difficult to have a social life, as it proved complicated to go anywhere and too much of a burden to prepare for guests, which was described as a form of isolation: ‘I consider it as a limitation. I really think it is, to be so restricted. I used to be able to walk everywhere. The worst thing is not being able to go out when I want to. It is too much of a strain for me to go to XXX nowadays. It is not feasible.’

Discussion

Methodological considerations

Rigour in the data collection was ensured by using the concepts of applicability, concordance, security and accuracy (26). In this study, applicability was based on the method and the recruitment process, which was intended to provide maximum information. Phenomenography is a method with high applicability for identifying varying human conceptions of a phenomenon (25). Applicability is achieved when the aim of the study has been fulfilled and the results provide a description of different conceptions. The participants were strategically selected to ensure a varied picture that would provide as many conceptions as
possible of the studied phenomenon, namely how patients suffering from chronic heart failure conceived the physical limitations related to activities of daily life. A limitation in qualitative research is that it is impractical for the researcher to use large, representative samples for obtaining data. Although qualitative findings cannot be generalised, they are important for the clinical care of the patient and promote thoughtful, reflective practice by revealing various conceptions of the studied phenomenon (23) and might be transferred to other individuals with similar conditions. In this study, 15 interviews were conducted by the first author, which is an adequate number when employing strategic selection, as it allows the emergence of different conceptions and the presentation of evidently results. The interview questions were planned together with the supervisors, who possess both professional knowledge of the topic and methodological expertise. Concordance was increased by a pilot interview, which was included in the study. Security was strengthened by the fact that the first author conducted all the interviews and made repeated comparisons between the raw data and the final aspects together with the supervisors. None of the participants were dependent on any of the researchers, which ensured that the results were not biased. Accuracy was established by the use of quotations connected to the aspects, which illuminated the participants’ conceptions.

Need of finding practical solutions in daily life

There were participants who changed focus because of their chronic heart failure and found other ways of performing the activities of daily life. They reported that a walking frame was a great help because it made it possible for them to perform activities bit by bit and with less strain. The participants experienced walking as one way to continue to perform activities of daily life, although they worried that they might suddenly need a rest. A Cochrane review revealed that training improves exercise capacity in patients in NYHA classes II and III (28) and that the long-term effects of physical exercise in patients suffering from chronic heart failure are in many ways similar to those observed in healthy subjects (29). Older adults have to adjust to and cope with variations in terrain and lighting, moving obstacles such as other people or vehicles and the difficulties brought about by changed speed, increased fatigue and perturbations of balance. According to Frank and Patla (30), walking is ‘a controlled state of falling in which older adults are only one step away from disaster’. Chronic heart failure is a complex illness with serious consequences for patients and families. In line with Ekman et al. (8), the participants in this study experienced themselves as a burden to others, both in terms of their need for help in everyday life and for causing worry. This is also in line with previous findings from studies by Mårtensson et al. (31, 32), who demonstrated that patients suffering from chronic heart failure and their spouses faced several difficult issues and that mild to moderate chronic heart failure can have a minor influence, whereas severe chronic heart failure requires major changes in their life. In accordance with Falk et al. (33), the participants sometimes saw their need for help in factual terms and made use of different types of home service, which relieved them of the feeling of being a burden or indebtedness. The constant need for planning described in the study included doing a small amount of shopping every day and making sure to park the car in a place where they could get back to it without difficulty. This is in contrast to the findings of Falk et al. (33), who indicated that patients found it difficult to plan, whereas the participants in this study stated that planning was an important aspect of daily life. For example, they described the need to plan and prepare their meals slowly to have the strength to eat them, which is in line with Jacobsson et al. (34).

Having realistic expectations about the future

The functional capacity to perform the activities of daily life becomes increasingly limited in line with advancing age and the decline is highly individual (35). In line with Rogers et al. (36), there were participants who perceived that their age and not only their chronic heart failure had an impact on their physical capacity. These individuals seemed more adaptive to physical limitations, as they accepted them as a natural part of the process of ageing and were thus more likely to try to attempt activities and test their functions, as they did not consider strain on the heart a problem. In line with earlier studies (37), the participants experienced a sense of satisfaction when they discovered that they still had the ability to be physically active and could continue doing the things they had performed before at the same level of strain, which is also supported by Falk et al. (33). One important goal in nursing should be to maximise functional ability in activities of daily life to help patients maintain quality. Participants described a loss of activities but then revealed that they had not attempted to perform them. When they tried and were successful, they became filled with satisfaction and self-confidence. This agrees with Europe and Tyni-Lenné (37), who found that the ability to perform even a low level of physical activities created a feeling of joy. Costello and Boblin (38) reported that this led to hope in the future. Lost fitness can be regained by means of regular physical activity, even in extreme old age (39) and most health benefits can be derived from regular activity of moderate intensity (40). This is supported by the results of this study, where the participants experienced continuous progress when they repeatedly and successfully attempted to perform activities. Europe and Tyni-Lenné (37) also demonstrated that men wanted to achieve improved physical capacity and expressed the belief that it is possible,
which is in line with the findings of this study. Memories are an important part of daily life when the patients can no longer perform all the activities they would like and, as demonstrated by Falk et al. (33), it is important to have the opportunity to reflect on past enjoyable experiences. Memories of a good life can sometimes induce a sense of calm and greater preparedness to die (41).

Not believing in one’s own ability

There were participants who reported avoiding activities that were difficult or exhausted them, to minimise their symptoms instead of attempting to perform them and evaluating the outcome. Such behaviour leads to a risk of underperformance. This is in line with previous findings, where Ekman et al. (42) pointed out that patients organise their life in a way that is compatible with their abilities and resources. Reduced exercise capacity is a key factor that limits activities of daily life, and patients become trapped in a vicious circle of inactivity and decreasing functional capacity (28). It is of great importance that nursing interventions aimed at patients diagnosed as suffering from chronic heart failure concentrate on establishing or re-establishing the patient’s self-confidence in his/her physical capacity. According to Collins et al. (43), there is a need for rehabilitation programmes of sufficient duration conducted by skilled professionals to support the patients to overcome fear and other perceived barriers to engage in such regular programmes of physical activity. Lack of interest as well as personal (e.g. physical symptoms) and environmental factors (e.g. the presence of barriers) hinder physical activity. Schutzer and Graves (44) stated that older people do not try to be physically active because they believe that they are too old and frail and tend to consider exercise as a recreational pursuit rather than a necessity for health promotion. The participants in this study had a fear of death or a more undefined fear of the future, which is in line with Falk et al. (33). Rodriguez et al. (45) found that patients felt they had no future and lived from day to day. The participants in this study were afraid to attempt to reach their limits in terms of physical activities. Schutzer and Graves (44) reported that elderly people most frequently cite poor health as the main barrier to physical activity although the participants in their study did not explain the way in which poor health influenced them. Furthermore, there were participants that considered they already had sufficient exercise through the performance of activities of daily life. Patient behaviour is based on his/her understanding of signs and symptoms. If these signs and symptoms are not adequately explained, the patient is left to work things out for him/herself and may even arrive at the conclusion that physical activity is dangerous, as in this study. It is of great importance that healthcare professionals provide adequate information to ensure that patients are aware of the benefits and risks of physical activity and strain.

Losing one’s social role in daily life

There were participants who experienced a lack of content in their life as becoming a person who suffers from chronic heart failure. In line with Aldred et al. (46), the disease caused several participants to give up activities that they used to enjoy. This included physical as well as social activities such as visiting family or friends and cultural events like theatres and concerts. In line with a study that included only men (37), the participants in this study felt that they could not cope with the demands of their former social life as they no longer had the same physical capacity. However, the participants in our study did not experience a loss of mental capacity other than difficulties maintaining their concentration and interest long enough to do what was expected of them, which contradicts the findings of Europe and Tynni-Lenné (37). The lack of important content in life was also observed in a study by Aldred (46), where having to relinquish a long-held social role often caused significant distress (47) and the patients felt isolated because of being more confined to the home (46). In line with earlier findings (37), fatigue is a major problem described as a great need of sleep, which makes it impossible to perform activities throughout a whole day without taking a rest. This had an impact on the participants’ social life, as they found it difficult to leave the confines of their home because they experienced extreme fatigue. Inviting people to visit them was also problematic because of the necessity of tidying the house and preparing a meal. There were participants who described the importance of meeting other people and engaging in activities that have an impact on society, but the need to prove oneself made this difficult. This could concern, for example, becoming a member of a voluntary organisation.

Conclusion and implications

Patients suffering from chronic heart failure found new practical solutions to manage activities in daily life. One aspect concerned their willingness to change focus and identify other ways of doing important things. Accordingly, nurses play an important role in supporting the patients in this process, thus promoting a rich daily life. Patients had an incentive to maintain functions and activities to ensure a good quality of and strengthen their physical capacity in daily life. Facilitating patients suffering from chronic heart failure to maintain their quality of life and, if possible, continuously make progress is an important issue related to the nursing care of the patients. It is necessary to provide advice about the appropriate level of physical activity to help the patient to maintain his/her physical capacity in daily life. Inability to trust in their physical capacity in combination with experienced limitations in daily life prevented patients from attempting to increase their activities. This study illuminate the
uncertainty the patient perceive because of physical activity and it is necessary to be aware of the patients’ beliefs about physical capacity to improve their perceptions of the benefits of and reduce barriers to the performance of physical activities. Nurses need to inform patients suffering from chronic heart failure that fear of straining themselves or doing something wrong will result in underperformance. They also require knowledge of the principles of efficient physical training for patients suffering from chronic heart failure to ensure clarity when advising these patients to perform physical activities. The loss of a role in the society is important to stress and it is of great importance that nurses assist these patients to maintain their position and role in the family as well as society. Guiding the patients by providing information about important mental and physical issues in life should be a natural part of nursing care. There is a need to raise awareness among professionals of the profound impact of chronic heart failure on the lives of patients and carers as well as to explore how their needs can be more appropriately met.

Author contributions

Emma Pihl, conducted the interviews, analysed the material and wrote the manuscript. Bengt Fridlund, supervisor in making interview questions appropriate and additional evaluator in the categorisation procedure and in the writing of the manuscript. Jan Mårtensson, supervisor in making interview questions appropriate and additional evaluator in the categorisation procedure and in the writing of the manuscript.

References


Study II

Heart failure and physical limitations

Spouses’ Experiences of Impact on Daily Life Regarding Physical Limitations in the Loved One with Heart Failure: A Phenomenographic Analysis

Emma Pihl, MNSc, RN, Bengt Fridlund, PhD, RNT, and Jan Mårtensson, PhD, RN

Background: Physical limitation is a great burden for patients with heart failure, but little is known about how that affects spouses. Beneficial effects of support on the prognosis for the patient with chronic heart failure may come at a psychological and physical cost to the person providing the support.

Purpose: The aim of this study was to explore and describe how spouses perceive the physical limitations in patients with heart failure and the impact these limitations have on their daily life.

Design: A qualitative design with a phenomenographic approach was chosen for the study.

Findings: The informants were 15 spouses of heart failure patients. The spouses perceived a variety of aspects pertaining to how they perceive the physical limitations in the loved one with heart failure and the implication this had on their daily life. The referential aspects were: losing self-containment, missing community, accommodating to the situation and finding satisfaction in life.

Implications and conclusions: Awareness must be raised among health care professionals about the profound impact heart failure in loved ones has on the spouses and explore how the spouses' needs can be appropriately met. Since spouses have an important role to play in the management of heart failure, it is of great importance that nurses identify and support spouses to manage daily life activities. Taking care of the good days in order to have a rich life and to help spouses see possibilities is necessary since it is difficult to predict the future.

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Key words: activities in daily life, chronic heart failure, phenomenography, physical limitations, spouse

Comment les partenaires vivent les répercussions, sur leur vie quotidienne, des limitations physiques d’un être cher atteint d’insuffisance cardiaque: Une analyse phénoménographique

Introduction. Il est reconnu que les limitations physiques constituent un lourd fardeau pour les personnes atteintes d’insuffisance cardiaque, mais on connaît mal les répercussions de ces limitations sur leurs partenaires de vie. Le soutien offert à la personne atteinte d’insuffisance cardiaque chronique a des effets bénéfiques sur son pronostic, mais il peut avoir un prix, tant psychologique que physique, pour la personne qui le donne.

Objectif. Cette étude visait à explorer et à décrire comment le ou la partenaire d’une personne atteinte d’insuffisance cardiaque percevait les limitations physiques de cette personne ainsi qu’à examiner les répercussions de ces limitations sur la vie quotidienne du ou de la partenaire.

Plan d’étude. Il s’agit d’une étude qualitative menée selon une démarche phénoménographique.

Résultats. Les informations ont été obtenues auprès des partenaires de 15 personnes atteintes d’insuffisance cardiaque. Ces 15 partenaires ont remarqué que leur manière de concevoir les limitations physiques de leur être cher comporte divers aspects et qu’il y a des répercussions sur leur quotidien. Les aspects de référence étaient les suivants: perdre son autonomie, perdre l’appartenance à la communauté, s’adapter à la situation et trouver une satisfaction dans la vie.

Implications et conclusions. Il faut sensibiliser les professionnels de la santé aux répercussions profondes que l’insuffisance cardiaque d’un être cher peut avoir sur son ou sa partenaire, en plus d’explorer comment les besoins du ou de la partenaire peuvent être adéquatement satisfaits. Compte tenu du rôle capital joué par les partenaires dans la prise en charge de l’insuffisance cardiaque, il s’avère très important pour le personnel infirmier de reconnaître ces partenaires et de les soutenir dans la gestion de leurs activités quotidiennes. Puisque c’est difficile de prédire l’avenir, il faut profiter des bonnes journées pour avoir une vie enrichissante et aider les partenaires à entrevoir les possibilités qui s’offrent à eux.

Background
Chronic heart failure is a common condition among the aging population in Europe, a syndrome that occurs at a median age of around 75 years. Chronic heart failure affects approximately 10% of the elderly

(McMurray, 2002), implying that a considerable part of the elderly population either have chronic heart failure or live close to such a person. The severity of heart failure ranges from no physical limitations at all to major limitations in daily life. Overall, 40% of
patients admitted to hospital with heart failure are dead or readmitted within one year and 50% of patients are dead within four years (Dickstein et al., 2008). A diagnosis of chronic heart failure causes physical and emotional changes together with fear and uncertainty about the future (Mårtensson, Karlsson, & Fridlund, 1998; Pihl, Fridlund, & Mårtensson, in press). Older patients suffering from heart failure have significantly lower levels of physical health than those without heart failure (Pihl, Jacobsson, Fridlund, Strömberg, & Mårtensson, 2003). Findings indicate that the patients perceive a variety of aspects pertaining to these physical limitations in activities in daily life (Pihl et al., in press). A life-threatening disease implies a need for care and assistance from others, causing a need for social support. Chronic heart failure is difficult to live with, involving a burden on patients, their families and society (McMurray, 2002).

Mild to moderate heart failure can have a minor influence, whereas severe heart failure requires major changes in the lives of the couple (Mårtensson, Dracup, & Fridlund, 2001). These changes have great impact on the lives of the spouses while, at the same time, spouses have an important role in helping the patients handle the changes in their lives. The spouse’s role as a caregiver has changed over time from a natural caregiver, to a spouse who visited the loved one in the hospital, and now back towards a caregiver in the home setting. Caregivers for patients with heart failure should encourage the patients in self-care, monitor patient adherence to the treatment plan, get patients to medical appointments, and detect early signs of aggravation of the heart failure (Pattenden, Roberts, & Lewin, 2007). However, the beneficial effects of this support on the prognosis for the patient with chronic heart failure may come at a psychological and physical cost to the person providing the support.

Being the spouse of a patient with a life-threatening disease usually means a complicated life, with a number of new emotional and practical issues (Andershed & Termestedt, 1998). Older caregivers have significantly lower caregiver self-esteem and more health problems than younger caregivers (Saunders, 2008). Studies have shown that informal caregiving is associated with increased levels of emotional distress (Pincus & Sorensen, 2003), but there is no clear evidence that NYHA-class is related to spousal emotional distress. Higher NYHA-class in the patient was found to be related to poorer health in one study (Mårtensson, Dracup, Canary, & Fridlund, 2003) contrary to Rohrbaugh et al. (2002). Many family caregivers put their lives aside to provide care (Saunders, 2008) and this has an important impact on the daily life of the spouses. It is known that spouses influence the health of the patient (Rohrbaugh, Shoham, Cleary, Berman, & Evy, 2009), but not much is known about how the patients influence their spouses’ health and well being. It is important to focus on both members of the couple, lest crucial information about the influence of one person on the other in the relationship is neglected. There are studies, mostly in younger spouses, that illuminate problems with emotional distress (Pincus & Sorensen, 2003) and low quality of life (Rohrbaugh et al., 2009). Although chronic heart failure primarily affects older patients, little is known about how their spouses perceive the physical limitations of the patients and how this influences the daily life of the spouses. It is, therefore, of major importance to identify and improve the knowledge of physical limitations in the patients and the implications in the daily life of the spouses.

Purpose

The aim of this study was to explore and describe how spouses perceive the physical limitations in patients with heart failure and the impact these limitations have on the daily life of the spouse.

Method

Design and method description. The study took place in a county council area in the southwest of Sweden. Permission was obtained from the head of the cardiology department, as well from the ethics committee. An explorative and qualitative design with a phenomenographic approach was chosen in order to explore the qualitative variations in the participants’ conceptions of limitation in the physical function of the loved one and their impact in the daily life of the spouse. Phenomenography was developed in the early 1970s in Sweden within the domain of learning, but has since spread from the educational context to health science research (Sjöström & Dahan, 2002). Phenomenography aims to describe the various ways in which people conceive the world, as opposed to how the world really is, resulting in a description of the variations in the way a phenomenon is experienced (Marton, 1981), which has two aspects: structural and referential. These two aspects are connected to each other and appear at the same time when something is experienced. The structural aspect refers to the fact that when people experience something, they discern its parts from the context, the way they are related to each other and the way they relate to the whole. When the whole and the parts and the relationship between them are clarified, further degrees of meaning are discerned. The referential aspect is the overall significance attributed to a phenomenon and is built up by means of the different structural aspects that are part of the whole phenomenon (Marton & Booth, 1997).
Participants. The participants comprised 15 spouses of heart failure patients recruited from a heart failure clinic in a county hospital. The inclusion criteria were living with a patient with heart failure diagnosed by echocardiography and the ability to speak and understand the Swedish language. In accordance with the phenomenographic tradition (Wenestam, 2000), participants were strategically selected in order to obtain variation with regard to sex, age, place of residence, education and NYHA-class of the patient (see Table 1). Exclusion criteria were other serious physical or mental disorders in the patient or spouse. After a follow-up visit to the heart failure ward, the heart failure nurse asked the patients whether their spouses were interested in taking part in the study. If the patients considered it possible for the spouse to participate, the heart failure nurse explained the aim of the study verbally and provided each potential participant with written information. The potential participants were contacted one to two weeks later, giving them time to consider whether or not they wanted to take part in the study. They were informed that participation was voluntary, that they could withdraw at any time prior to the start of the analysis and that the interview data would be treated confidentially. The participants were not dependent on the researchers with regard to care for their loved ones. All agreed to participate. Before inclusion, written consent was obtained from all participants.

Data collection. The interviews were conducted by the first author (EP) during a six-month period. A pilot interview was performed to test the validity of the opening questions. The author and supervisors (BF, JM) deemed these appropriate and only minor changes were made in the questions; the pilot interview was included in the data. The participants chose the location for the interviews; 10 took place in the participants’ homes and five at the hospital. The interviews lasted up to 50 minutes and were semi-structured in order to capture how the spouses of patients with heart failure experienced physical limitations in the loved one in daily life. The opening questions were: "What are daily

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<th>Table 1: Demographic and clinical characteristics of the participating spouses (n = 15) and their loved ones</th>
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<td>Sex</td>
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<td>High school &lt; 12 years</td>
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<td>University</td>
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Table 2: The seven steps of data analysis in accordance with the phenomenographic tradition of Dahlgren and Fallsberg (1991)

1. Familiarization. The interviews were read carefully to become familiar with the text.

2. Condensation. The most significant statements made by the participants were selected as representative of the entire dialogue about the phenomenon. These were viewed in the light of two parts, in relationship to other statements from other interviews and in relationship to the whole of the actual interview.

3. Comparison. The statements were compared in order to identify variation or agreement.

4. Grouping. Data that appeared to be similar were grouped together.

5. Articulating. A preliminary attempt was made to describe the essence of the similarity within each group of statements. Groups were then put together by analysis of the internal relations of the statements and structural aspects were formed.

6. Labelling. The various aspects were denoted by formulating an appropriate linguistic expression and referential aspects derived.

7. Contrasting. The obtained aspects were compared in terms of similarities and differences.

Steps 4 and 5 were repeated several times before the analysis was deemed satisfactory. The referential and structural aspects that emerged were formulated to describe the context and illustrated by quotations.
life activities for you?” “Have your daily activities changed since your loved one got sick?” and “Are there any physical activities in your daily life that your spouse finds difficult to manage?” These were followed by probing questions such as: “How does that influence your daily life?” and “Can you describe in more detail?” The interviews were audiorecorded and transcribed verbatim.

Data analysis. The first author performed the analysis. The supervisors served as additional evaluators in the categorization procedure. The analysis was performed in accordance with phenomenography and the seven steps described by Dahlgren and Fallisberg (1991). (See Table 2.)

Findings

The spouses perceived a variety of aspects pertaining to how they conceive the physical limitations in the loved one with heart failure and the implication this had on their daily life. (see Table 3). The referential aspects were: Losing self-containment, misting communality, accommodating to the situation, and finding satisfaction in life.

Losing self-containment comprised restriction in own experiences due to physical limitations in the loved one. No plans could be made since it was never sure that the loved one could manage the physical strain. Along with loss of activities, there was continuous worry for the loved one. Balancing the life of the loved one had become an important task. Overload in daily life and situations where the spouses’ own health status had worsened due to the life situation had emerged. Structural aspects were:

Balancing the life of the loved one where spouses experienced the loved one as dependent on them for physical concerns and that they must continuously show consideration for the loved one. This included taking responsibility to help the loved one keep up former physical activities, handle irritation and disappointment in the loved one when things did not go as planned, as well as restricting the physical activities of the patient when things seemed to be too much: “...I know, deep down, the backlash will inevitably come. If I can get him to rest for a moment or take a coffee break or something, I can prevent something. Then it is fine for him to continue later, but a pause is necessary. We people are all so different”.

Being overloaded comprised getting strained due to the physical limitations of the loved one. They were forced to take on more practical and mental responsibilities in the home than before the illness. Spouses did only what was necessary outside the home and perceived a loss of own time. There were even spouses who described a worsened health status in themselves when physical limitations in the patient and an increased strain in daily life had led to new symptoms: “Well, I’m alone in everything // But I’ve no problems with that because I’m the type who does it, as long I can. But then the high blood pressure comes...”

Living with worries was characterized by spouses as living with continuous worries about the physical condition in the loved one, while other spouses perceived a decrease in worries over time. Not knowing what physical strains or physical activities in daily life could be dangerous caused anxiety. Spouses described worries about practical issues, as well as a strong fear of the future: “That you constantly have a worry... that something can happen. That you continuously feel that you have the responsibility at home”.

Support to manage practical situations included help from family, as well as from others, since the

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<th>Referential aspects</th>
<th>Structural aspects</th>
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<td>Losing self-containment</td>
<td>Focusing on the limitations the spouses experience due to physical limitations in</td>
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<td>the loved one. Aspects deriving: balancing the life of the loved one, being</td>
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<td>overloaded, living with worries, needing support to manage practical situations,</td>
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<td>inability to plan, loss of what is not doable and sacrificing due to guilt.</td>
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<td>Missing communality</td>
<td>Focusing on the loss of fruitful relationship and common experiences. Aspects</td>
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<td>deriving: Lack of intimacy with the loved one, loss of the loved one, not being</td>
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<td>paid attention to and lacking mutual experiences.</td>
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<td>Accommodating to the situation</td>
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<td>naturally. Aspects deriving: Keeping the mood, accepting change in life, being the</td>
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<td>Finding satisfaction in daily life</td>
<td>Focusing on the good parts in life and positive thoughts about the future. Aspects</td>
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<td>deriving: Identifying personal space, being contented with life, living with</td>
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<td>positive thoughts about the future and prioritizing collaboration.</td>
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physical capacity in the loved one had decreased and
the spouse could not manage daily life activities on
her/his own. This was perceived as both positive and
negative, as well as something the spouses had to
adjust to, because of the situation, but also because of
sex of the spouse: “In the summer I have to mow the lawn
and take care of the rest. I had to accept a little help last
summer because I couldn’t do it, naturally. Some things a
woman can’t do, and that’s that”.

Inability to plan concerned the difficulties and
impossibility to plan activities in advance due to the
physical limitations and changeable nature heart
failure caused, but also because of worry for the loved
one. These difficulties, for example, made travelling
different: “…our travelling has changed, so to say, we have
had to postpone everything to the future // have not been
able to plan anything, it is the condition for the day that
decides”.

Loss of what is not double was characterized by the loss of
former activities and social gatherings. The perception of
lost activities ranged from travelling on holidays, to
travelling to relatives and taking day trips. Social
gatherings had become a smaller part of life than
desired: “…that has also diminished very, very much,
because he has been so tired and I have not been able to
invite so many…”.

Sacrificing due to guilt was characterized by the spouses’
description of decisions to forgo activities of their own
when the loved one could not participate. If the loved
one could not do the activities they used to do together,
the spouses would not let them down by doing the
activities anyway: “…walk up the mountain and take a
long hike, bring coffee and go out and look at birds and these
activities we have done together before, these I don’t want to
do if he is not with me…// that would make me feel so very
disloyal”.

Missing communality was characterized by loneliness,
since the loved one did not have the former physical
strength. Spouses missed the daily life experiences
with the loved one and missed the person the loved
one used to be. Not being seen and having their needs
go unnoticed by people around them was a double
loneliness. Spouses were not given recognition for their
own needs due to physical limitations in the loved one
and were not seen as the resource they wanted to be.
Structural aspects were:

Lack of intimacy with the loved one was characterized by
spouses desiring, but not receiving the same mental or
physical connection to the loved one as before. Retirement
was supposed to allow for more quality
time together, but that was not possible. The sexual
part of life was seen as a problem, possibly due to
physical limitations in the loved one, but also cuddling
had decreased: “I think that that part influences me a lot. I
mean I think that I could handle life much better. On the
whole. // Because then you at least had a little life left, you
could still feel closeness with each other”.

Loss of the loved one concerned that the loved one had
changed in personality and spouses had the perception
that this had to do with diminishing physical strength,
which made them different from what the spouses
were used to: “…I can confess that I feel irritated, but at the
same time I know I have… I have such a clear picture of X as
he was before so I… I mean this is a different X. When he’s
sick”.

Not being paid attention to was described as not being
seen by the loved one, family, friends or others. For the
family and health care professionals, the focus was on
the loved one and spouses experienced that they were
seen as unimportant. In the family, this meant lack of
support in daily life, whereas in health care it had
many implications. On one hand, the spouses did not
get support for the needs that derived due to physical
limitations in the loved one. On the other hand, they
did not get recognition for their effort to keep up and
shoulder the tasks of daily life and, finally, spouses
were not recognized as a resource: “There is never
anyone who has asked how I feel. // I think the health care
must realize that a lot… that the person standing beside the
patient has a very big role in this. If he feels good, less good
or catastrophic”.

Lacking mutual experiences concerned the loss of doing
activities together. The reason for this could be due
to both the physical limitations in the loved one and
because the spouse could not perform many chores, for
example, driving, which the loved one used to do but
could no longer manage. This included simply the
recognition that this was the situation and something
else had to be done, or it could be perceived as
something negative: “…we often went to concerts and
musical church services and he thought…thus, we did a lot
of this. // And that part we did together is also gone”.

Accommodating to the situation was characterized by
the future being viewed with fear, as well by the
statement “This is the life we have, and this is it”. Thus,
they took increasing responsibility for activities in daily
life left undone by the loved one. Accepting the life
situation and seeing change as natural had occurred
and a responsibility to keep up the mood had been
accepted. Structural aspects were:

Keeping the mood was characterized by the spouse
shouldering the responsibility in the relationship to
keep up the mood for him/herself and for the loved
one. This included smoothing over the effects of
physical deterioration in the loved one and hiding
one’s own sadness over the changed daily life in order
to hold the loved one’s lust for life alive. It was a
double burden for the spouse: “It is like to pep up him too / so it gets double for the spouse. I have to pep up myself too, to be able to manage. If it gets double then”.

Accepting change in life meant that changes, including physical limitations due to heart failure in the loved one, managing tasks in daily life and getting used to the life situation were perceived as irrefutable facts of life. There were spouses where the decline in the loved one had come over a long time, which gave them the possibility to adapt gradually. Others found it to be an expected and accepted part of getting older. There were participants who experienced it as something negative and others accommodated to it more easily: “I still think that you automatically try to make the best out of something that has become rubbish in your life”.

Being the prime mover in the couple was perceived both as positive and negative. Spouses described the need to always take the initiative and to continuously have to suggest daily physical activities. The lost initiative in the loved one was experienced as a part of lost strength. Being constantly required to take initiative and make suggestions was considered stressful. Activities had to be forced to happen: “...I have to nag and then, when we do it, I don’t think it’s fun... because I have worked with it so long”.

Taking more responsibility in daily life included positive and negative perceptions of practical issues, as well as the overall responsibility in daily life. There were spouses who found it natural while others found it more difficult. Practical issues concerned, for example, the daily running of a home and taking care of a sick loved one and the overall responsibility for everything: “I have to take care of it all. He is... maybe it is forgetful or something...”

Taking one day at a time included that the future could bring further changes and spouses did not want to think about it. It was expressed as it is the way it is and it is important to be happy as long as it is possible to stay together. There is no need to think about the future and the problems that might come with it: “No, if you have to take the problems when they come. It is no use building mountains”.

Finding satisfaction in daily life meant that the spouses had what was needed in daily life, but also that they perceived the need to find new activities to do on their own or to slightly change their own existing activities. To be together was important and prioritized and spouses had positive thoughts about the future and the possibilities the future held. Structural aspects were:

Identifying personal space included finding new activities or situations that became important when the loved one could no longer join physical activities, but also re-evaluating existing activities or appreciating well-known situations. Spouses pointed out the importance of finding activities in order to manage their daily life that had become so restricted due to the physical limitations in the loved one. To have time for themselves was sometimes a new experience: “... that has come now. Earlier we did everything together. At least most of it”.

Being contented with life comprised no change in life since diagnosis was set and regular activities could continue for both spouse and loved one. It also meant that it was nice to reduce activities, due to physical limitations in the loved one, and to take it slower than before and to experience satisfaction in having what is necessary in daily life: “It does not affect me much, really... I think it is lovely not to do so much. I like to be at home after work...”

Living with positive thoughts about the future concerned the spouses’ belief that the physical capacity in the loved one would improve and enable more mutual physical activities. This thought was important in managing daily life. Taking care of each day was important. When the loved one felt well, the spouse could also feel well. Even though certain activities were not possible to manage at the time, plans for the future were present: “You have to see that new destinations will come instead. They only get moved forward. The experience. The islands are still there, so to say”.

Prioritizing collaboration concerned changes in personal activities that sometimes had to be adjusted due to decreased physical capacity in the loved one. The changes ranged from no need at all to do their own things, to changing spouses’ activities to facilitate mutual experiences, and to finding completely new activities that could be done together. It was important to spend time together and other things had lost meaning: “We have the car and we have the cabin and we go there and enjoy ourselves. Light a fire and cook and have it generally nice. Then it’s good!”

Discussion

Methodological considerations. Rigour in the data collection was ensured by using the concepts of applicability, concordance, security and accuracy (Fridlund & Hildingh, 2000). Applicability was based on the method and the recruitment process, which was intended to provide maximum information. Phenomenography is a method with high applicability for identifying varying human conceptions of a phenomenon (Marton & Booth, 1997). Applicability is achieved when the aim of the study has been fulfilled and the results provide a description of different conceptions. The participants were strategically selected to ensure a varied picture that would provide as many conceptions as possible of the studied
phenomenon. Although qualitative findings cannot be generalized, they are important at an individual patient level, as well as for the clinical care and they promote thoughtful, reflective practice by revealing various conceptions of the studied phenomenon (Göystrom & Dahlgren, 2002) and might be transferred to other spouses with loved ones with similar conditions. The number of interviews (15) is adequate when employing strategic selection, as it allows the emergence of different conceptions and the presentation of evident results. The interview questions were planned with the supervisors, who possess both professional knowledge of the topic and methodological expertise. Concordance was increased by a pilot interview, which was included in the study since it was considered to be appropriate. Security was strengthened by the fact that the first author conducted all the interviews and made repeated comparisons between the raw data and the final aspects together with the supervisors. None of the participants were dependent on any of the researchers, which ensured that the results were not biased. Accuracy was established by the use of quotations connected to the aspects, which illuminated the participants’ conceptions.

Losing self-containment. Spouses took responsibility in helping the loved one perform a reasonable level of physical activity. Spouses in the study described an overload in daily life. In line with earlier findings (Bakas, Presler, Johnson, Nauser, & Shaneyfelt, 2006; Saunders, 2008), there were spouses whose own health status worsened. In contrast to Dracup et al. (2004), spouses found caregiving tasks burdensome when demands in daily life increased. Lack of knowledge about heart failure caused worry. Not knowing what level of strain was acceptable and what level was dangerous caused fear, which is also seen in patients with heart failure when it comes to physical capacity (Pihl et al., in press). Spouses mentioned the rest of the family as possible helpers, but spoke of the need for home service to spare the total family burden. Planning daily life had become impossible since the physical limitations in the loved one could change radically from one day to another, which gave a sense of lost control in daily life. This is in contrast to patients with heart failure where planning in daily life has been described as necessary (Pihl et al., in press). Spouses were limited in daily life in activities outside, as well as inside the home and spontaneity was lost due to physical limitations in the loved one. It was not possible to do whatever they wanted on a particular day, for example, to take advantage of a day with good weather. Travelling and experiencing new surroundings had become much less a part of life than previously desired. Exploring had become restricted, both in small daytrips and travelling longer distances.

Social gatherings with friends and family were difficult to manage due to fatigue in the loved one. Spouses stated that the loved ones did not stop them from doing activities without them, but guilt was nevertheless present in the spouse. The guilt could be because the activity was once a common issue in which both had enjoyed or it could be an undefined sense of letting the loved one down by doing something that was impossible for him/her. Reduction in activities is in line with Saunders (2008) where a majority of caregivers eliminated things to provide care, but in that study, guilt was not present.

Missing communality. Spouses missed former physical performance together, but also the moments of feeling akin and did not understand why the sexual part decreased. This was described as a loss that was difficult to discuss with the loved one. The need for more specific information about sexual activity in the couple has been pointed out (Westlake, Dracup, Walden, & Fenarow, 1999) and this is an important topic in the care of heart failure patients and their spouses. Also cuddling had decreased and this was even more difficult to understand. Spouses tried to fill daily life with meaning through affinity and when this was impossible, the daily life was difficult to bear. Not being paid attention to, either in their efforts to help the loved one or in their own personal needs, made the spouse unimportant and an outsider (Svedlund, Daniellson, & Norberg, 2001). There were spouses who thought of themselves as important for the loved one’s well being. They believed they had a large impact on the course of the disease, as well as the emotional status of the loved one. In the health care system, however, spouses thought they were not seen as the resource they experienced themselves to be. Clark and Dunbar (2003) showed, as in this study, that spouses described a high burden in daily life activities when the loved one returned home from hospital, due to the loss of physical capacity in the loved one. It has been stated that when heart failure caregivers are offered involvement in discharge planning, satisfaction increases, which is in line with the present study (Bull, Hansen, & Gross, 2000a; Bull, Hansen, & Gross, 2000b). Doing daily life activities together had become a smaller part of life than desired, especially since retirement was actually seen as a possibility to partake in more mutual activities. Decreasing mutual activities were partly due to the fact that the loved one could no longer perform necessary physical activities or that the spouse could not compensate the loss of function in the loved one, for example, in driving a car. The couple was forced to stay at home and spouses found manageable alternative activities. However, there were also spouses who found this a great loss, missing, for example, former common cultural events.
Study III

**Accommodating to the situation.** Spouses tried to never show the loved one their own sadness or worry. When the loved one expressed sadness or anger about physical functions, the spouse perceived a responsibility to say something positive. Successive decline in the patients’ physical capacity allowed the spouses to become accustomed to the situations in daily life and not everything was reflected upon. Spouses who accepted this decrease and who changed the activity pattern in their own lives, as well as that of their loved one, could think of this as a part of getting older, as patients did in Pihl et al. (in press), but also that this was for a limited period of time. When the loved one stopped taking initiative in daily life, the spouses kept the life they used to have together or that the loved one used to have. Spouses made sure that the loved one was engaged in their own activities or they did these activities together. Always having to decide what to do and when to do it were experienced as troublesome and a strain. It even happened that activities had become boring because of the need to nag in advance. Caregiver burden in heart failure has been associated with a greater number of caregiving tasks (Scott, 2000) and the spouses’ physical capacity. In this study, did not always meet the needs of daily life and taking care of a home, even though the spouses took the overall responsibility. Spouses did not want to think about the future due to the uncertainty of what the future might bring. They preferred to take one day at a time. Other spouses lived the way they were accustomed to and desired, since it was impossible to predict any negative events, even though this sometimes was due to ignorance. More information is needed. Walden et al. (2001) found that honest explanations about the heart condition and information about what to do in case of an emergency is warranted. Solving problems the day they occur instead of worrying in advance helped spouses to manage daily life.

**Finding satisfaction in life.** When the physical capacity in the loved one decreased and performing common activities had become impossible, it became important for the spouses to do things on their own. In the heart failure area, personal space in spouses is not discussed often. However, spousal caregivers have generally been found to report greater caregiving strain than non-spousal caregivers. This might have to do with the lack of independence, own space and breathing holes in the daily life (Ziegert, Fridlund, & Lidell, 2006). Personal space was described as time on their own, but also doing things with others, without the loved one. Nevertheless, frequent caregivers stated that they do not meet friends as often as they would like (Miller et al., 2001). There were spouses who found it positive not to be as active as they once were, and were satisfied by just being together with the loved one.

Experiences of not being forced to change anything in daily life since the diagnosis was set could be an expression of small amounts of physical activities earlier in life or that no changes had yet occurred in the physical capacity of the loved one. Activities were postponed, but spouses had the hope that it would be possible to do activities later on in life. It was important to try to do what was possible that particular day, but there was a conviction that it would be possible to do what was desired in the future. There were spouses who expressed plans about the future and plans for future activities were made. Spending time together was important and spouses made efforts to ensure they did activities together. The need for the spouses to do their own activities in daily life had been reduced since the loved one’s illness and finding new activities that could be done together had become important to keep the sense of collaboration in the couple. The importance of being together and doing things together made for joyful experiences (Brännström, Ekman, Boman, & Strandberg, 2007).

**Conclusions and Implications**

Spouses lost self-containment in the daily life due to the physical limitations in the loved one with heart failure. Since spouses have an important role to play in the management of heart failure and since caregivers who have high levels of stress and depression may be less able to fulfill their caregiver role, it is of great importance that nurses identify and support those spouses who find it difficult to manage daily life activities. The nurses should support the process and encourage willingness to seek external help. Spouses are important partners in providing care. However, they cannot provide care alone. They need guidance, support, and skills to manage care that is often complex. The absence of a fruitful relationship with the loved one, and also with health care professionals are obstacles to a rich life for the spouse. Nurses and other health care professionals need to see the patient and spouse as a team where it is important to fulfill the needs of both individuals. Information ought to be given routinely to heart failure patients and their spouses about living with and managing heart failure. Even though spouses in the present study are older, they miss sexuality and cuddling. Information about the safety of sexual activity must be provided. Good information and seeing the couple as a team lays the foundation for a good relationship within the couple, which is necessary for the possibility to handle the future. Spouses experience themselves as the prime mover in the couple. This includes travelling, day trips and keeping the loved one physically active. Uncertainty is expressed about the proper amount of physical activity and advice about physical activity
must be provided by the nurse in order to help the spouse in the daily life handling of the loved one. Information must also be provided by the nurse about taking care of the good days in order to have a rich life and to help spouses see possibilities, since it is difficult to predict the future and spouses found it difficult to plan in advance. Awareness must be raised among health care professionals about the profound impact heart failure in loved ones has on the spouses and explore how the spouses’ needs can be appropriately met.

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References


Exercise in elderly patients with chronic heart failure in primary care; effects on physical capacity and health-related quality of life.

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Study IV
Exercise in elderly patients with chronic heart failure in primary care; effects on physical capacity and health-related quality of life.

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**Abstract**

*Introduction:* Chronic heart failure (CHF) limits exercise capacity which influences physical fitness and health-related quality-of-life (HRQoL).

*Aim:* The aim was to determine the effects on physical capacity and HRQoL of an exercise programme in elderly patients with CHF in primary care.

*Methods:* An exercise intervention was conducted as a prospective, longitudinal and controlled clinical study in primary care in elderly patients with CHF. Endurance exercise and resistance training was conducted as group-training at the primary care centre and as home training. Follow-up on physical capacity and HRQoL was done at 3, 6 and 12 months.

*Results:* Exercise significantly improved muscle endurance in the intervention group (n=29, mean age 76.2 years) compared to the control group (n=31, mean age 74.4 years) at all follow-ups except for shoulder flexion right at 12 months (Shoulder abduction p=0.006, p=0.048, p=0.029; Shoulder flexion right p=0.002, p=0.032, p=0.585; Shoulder flexion left p=0.000, p=0.046, p=0.004). Six-minute-walk-test improved in the intervention group at 3 months (p=0.013) compared to the control group. HRQoL measured by EQ5D-VAS significantly improved in the intervention group at 3 and 12 months (p=0.016 and p=0.034) and SF-36, General Health (p=0.048) and Physical Component Scale (p=0.026) significantly improved at 3 months compared to the control group.

*Conclusion:* This study shows that exercise conducted in primary care and in the patients’ homes could be used in elderly patients with CHF. The combination of endurance exercise and resistance training has positive effects on physical capacity. However, the minor effects in HRQoL needs further verification in a study with a larger study population.

*Keywords:* Chronic Heart Failure; Elderly; Exercise; Health-related quality of life; Physical fitness; Primary Care
Introduction

Chronic heart failure (CHF) is a severe condition with poor prognosis and it has a large impact on physical fitness since exercise capacity in patients with CHF is approximately 50-75% of normal age and gender predicted values (1). Physical impairment is described as a striking finding in older adults with CHF (2) and it negatively impacts health-related quality of life (HRQoL) (3) and the activities of importance in life (4). Further, increased effort and decreased quality in performance of activities of daily living (ADL) is described in patients with CHF (5). The strain from low levels of physical activity increases as NYHA-class advances or CHF severity progresses (6). ADL are important clinical aspects in chronic disease, especially in the case of frail, older patients in whom prolongation of life may not always be the primary aim of therapy (7). The public opinion is that exertion should be avoided when having CHF (8), but research shows that exercise is beneficial (9, 10) and safe (6) for the patient. However, only a small proportion of patients with CHF participate in exercise and one reason of this is lack of access to hospital based exercise (11, 12). Scientific literature in home-based exercise (mostly arranged from hospital) has increased during the last decade. Inconclusive results have been shown with beneficial effect of distance walked (13) and HRQoL (14) or neutral effect of distance walked (15, 16) and HRQoL (15). The greatest numbers of patients with CHF are managed in primary care, but little research concerning the management in this setting has been conducted. With a growing number of elderly patients with CHF diagnosed and treated in primary care the demands increase to develop management and exercise programmes that could also be used in primary care. Accordingly, the aim of this study was to determine the effects on HRQoL and physical capacity of an exercise programme in elderly patients with CHF in primary care.
Methods

Study Design and Setting

This study was conducted during 2006-2009 as a 12-month prospective longitudinal and controlled clinical study of patients with CHF treated in primary care in three different Swedish county councils comparable in size and citizens in the catchment area. All patients, recruited from four primary health care centres in one of the county councils participated in the intervention group and patients recruited from the other two county councils constituted the control group. Ethical approval was given from the Regional Ethical Review Board in Linköping. The investigation conforms with the principles outlined in the Declaration of Helsinki (Br Med J 1964;ii:177).

Participants

Inclusion criteria were CHF, diagnosed by echocardiography and atrioventricular plane displacement <10 mm or in atrial fibrillation <9 mm, and NYHA-class II-III. Exclusion criteria were peripheral vessel-disease, chronic lung disease, status post stroke or other disease that made the measurements for the study impossible. A total of 152 patients were screened for participation and 59 were found eligible. 28 patients were recruited to the intervention group and 31 were recruited to the control group (Figure 1). The control and intervention groups were matched in terms of age, sex and NYHA-class. Baseline characteristics of the study population are given in Table 1.

Programmes

Intervention programme

The intervention programme comprised aerobic exercise as well as peripheral muscle training. The duration of the intervention was 12 months and was individually planned depending on the patient’s physical fitness. At two occasions after the baseline measurements, the patients visited a physiotherapist in primary care oriented in exercise for patients with CHF. At the first occasion the home based exercise programme was conducted and at the other occasion the exercise programme at the primary care centre was prescribed. The amount of repetitions and the load the patients used in the exercise was approximately 75 % of 1 repetition maximum (RM) and was estimated with Borg perceived exertion scale to level 15, which is strenuous (17). During the first 6 months the patients exercised once a week in a group at the primary care centre and three times a week at home. The group exercise started with common modulated warm-up exercises (10 minutes) with standing, walking and sitting exercises
accompanied by music. Thereafter, the patients performed their individual exercises which consisted of lower and upper body resistance training (45 minutes) and finally a period of active recovery exercises (5 minutes). The home based exercise programme (45 minutes) consisted of endurance exercise and peripheral muscle training and the resistance was regulated with a resistive elastic band (Jpm products, Hertsfordshire, United Kingdom). During the last six months of the intervention patients exercised three times a week at home and once a month at the primary care centre.

**Conventional Care**

The conventional care in the control group was performed according to local clinical guidelines in the two county councils in line with ESC guidelines (6).

**Data collection**

Data, physical tests and questionnaires, were collected at baseline and after 3, 6 and 12 months.

**Test of physical capacity**

**Bilateral isometric shoulder abduction**

Patients sat on a stool with their back touching the wall with one kilo dumbbell in each hand and both arms elevated to 90 degrees shoulder abduction. This position was kept as long as possible. The patient was instructed to correct the position once during the test and the second time the test was discontinued. The seconds of the 90 degrees angle of abduction was recorded. The reliability for the test in patients with CHF is very good (18).

**Unilateral isotonic shoulder flexion**

The patient sat on a stool with their back touching the wall and a weight (three kilos for male patients and two kilos for female patients) held in the hand of the arm to be tested. The patients were asked to elevate the arm, from 0 to 90 degrees flexion as many times as possible, with a speed of 20 lifts per minute using a metronome. The patient was instructed to correct the flexion once and the second time of an incorrect flexion the test was discontinued. The number of flexions was counted for each arm. The reliability for the test in CHF patients is very good (18).

**Six minute walk test**

A standardised six minute walk test (6MWT) (19) was used to assess exercise capacity related to ADL. The track was 30 meters and standardised encouragement was given to all
participants every minute. 6MWT provides valid, reliable and important information regarding the individual’s functional capacity (20) in ADL (19).

**Questionnaires**

**Patient-specific functional scale**

The patient-specific functional scale (PSFS) is a standardised instrument based on the individuals’ self-rated obstacles for activity. The patients identified activities difficult to manage due to current trouble and the severity was rated on a visual numeric rating scale 0-10. PSFS is a valid and reliable instrument in patients with mechanical low back pain (21), but it has to our knowledge not previously been tested in a population with CHF.

**Disability Rating Index**

The Disability Rating Index (DRI) questionnaire reflects the informants’ opinion of his/her disability in 12 items concerning physical function as well as actual capacity. The informants marked on a 100 mm visual analogue scale (VAS) in accordance to his/her own presumed ability to perform daily physical activities in question. The DRI is developed in Sweden and is a valid and reliable instrument, tested in healthy subjects and patients under rehabilitation due to neck/shoulder/low-back pain, arthritis and multiple sclerosis (22). Cronbach’s alpha in this study was 0.90. The DRI is to our knowledge not used earlier in patients with CHF.

**Short Form -36**

Short Form-36 (SF-36) is a generic HRQoL instrument which comprises eight domains and two summary measures, physical and mental (23). SF-36 is well established, frequently used, has high reliability and validity (24, 25) and SF-36 has previously been used among patients with CHF (3, 26, 27). We wanted to compare the HRQoL measured by SF-36 with age and gender-matched norm populations for the patients in the intervention group and the control group. The norm data were obtained from the Healthcare Research Unit, Institute of Internal Medicine, Sahlgrenska University Hospital, Gothenburg University, Gothenburg, Sweden responsible for the validation of the Swedish version of SF-36 (28).

**Minnesota Living with Heart Failure Questionnaire**

The Minnesota Living with Heart Failure Questionnaire (MLHFQ) is a disease specific HRQoL instrument with 21 items designed to measure the informants’ perceptions of the effects of CHF in daily life in terms of total, physical and emotional scores (29, 30). MLHFQ is deemed valid and reliable (30). A study on elderly patients with CHF in Sweden (31) shows that the Swedish version of MLHFQ is also both valid and reliable. Cronbach’s alpha in this study was 0.88 in the total scale, 0.89 in the physical subscale and 0.74 in the emotional
subscale.

**EQ5D-VAS**

EuroQol-5D (EQ5D) is a measure of generic self-perceived health status which obtains a self-rating of the overall health of the informant (32). A visual analogue scale (VAS) anchored at zero indicates an overall valuation of the current state of health. Validity, reliability and responsiveness for EQ5D-VAS have been tested in different populations with satisfying results (32, 33). EQ5D-VAS is frequently used in many clinical areas, among those cardiovascular diseases (34).

**Hospital Anxiety and Depression Scale**

The Hospital Anxiety and Depression Scale (HADS) identifies symptoms of anxiety and depression among patients in non-psychiatric hospital clinics (35). HADS focuses on relatively mild degrees of disorder and items are selected in order to distinguish between anxiety and depression. HADS is a valid and reliable instrument (36) which exists in a Swedish version. HADS is newly used in the field of CHF and exercise (16). Cronbach’s alpha was 0.89 in the anxiety scale and 0.6 in the depression scale.

**Statistical analysis**

With 60 patients in each group (intervention and control) it was deemed possible to detect a 20% difference in HRQoL between the groups (two-sided alpha level =0.05, beta =0.80). The analysis was performed using SPSS 17.0 (37). To explain the characteristics of the studied population Chi-2 and Student’s t-test was used, see Table 1. Delta values (Δ-values) from ordinal and not normally distributed data in ratio level were analysed with Mann-Whitney U-test, Δ-values from normally distributed data were analysed with Student’s t-test.

**Results**

At baseline there were no significant differences between groups regarding demographics, physical tests and questionnaires, Table 1 and 2. However, there were significantly more patients treated with aldosterone antagonist and beta blockers in the control group at baseline, Table 1.

**Physical capacity**

Exercise significantly improved muscle function compared to the control group at 3, 6 and 12 months except for shoulder flexion right at 12 months (Shoulder abduction p=0.006, p=0.048,
p=0.029; Shoulder flexion right p=0.002, p=0.032, p=0.585; Shoulder flexion left p=0.000, p=0.046, p=0.004, respectively), Figure 2. Also 6MWT improved at 3 months (p=0.013), Figure 3. PSFS or DRI showed no significant changes between the groups, Table 2.

**Health-related quality of life**

A significant improvement was seen in SF-36 in general health and physical component scale in the intervention group at three months (p=0.048 and p=0.026, respectively) compared to the control group. The MLWHF physical scores improved at three months (p=0.008) and the EQ5D-VAS was improved significantly at 3 months (p=0.016) and 12 months (p=0.034) compared to the control group. HAD did not significantly change between groups, Table 2.

**Discussion**

The findings from this study demonstrated that a combined aerobic and resistance exercise programme in a combined setting of primary care centres and patient homes was feasible and improved the physical capacity of importance for a range of ADL, but had minor effect on HRQoL. During the study period the control group deteriorated in physical capacity.

**Physical capacity**

This study shows evidence that exercise had positive effects on physical capacity in terms of muscle function in arms and shoulders as well as distance walked. The significant improvements in the upper body were persistent over time except for right shoulder flexion at 12 months. Since sufficient physical capacity is important for elderly patients in order to maintain functional independence in daily life the improved physical capacity in the upper body is important. It gives possibilities to improve tasks belonging to ADL and with greater efficiency perform such tasks. Patients avoid tasks that make them strained and have different tendencies to challenge the physical limitations in daily life (4). If the strain is decreased through exercise, the opportunity to withhold or even improve activities rises.

No significant improvements were present in the PSFS. However, patients value different activities as important which is necessary to consider in the care of the patients. Identifying the most important activities for the patients and using these activities as a beacon when the exercise programme is prescribed might enhance interest in exercise and adherence to the same thereby giving a positive outcome in the patients’ life.
At 3 months significant improvement in 6MWT was seen, but this was not persistent at 6 and 12 months. However, the intervention group kept a positive outcome during the intervention whereas the control group deteriorated, Figure 3. Our results are in line with earlier findings from meta-analysis where a significant improvement in the 6MWT was identified with a mean increase of distance of 30 meters in home-based exercise (38) and 46 meters when including hospital- as well as home-based exercise (39). Minimum clinically important change in 6MWT is considered 20-30 meters in elderly patients (40, 41) which was shown at 3 and 6 months.

The lack of significant improvements in the intervention group in DRI might be due to an excess of items measuring the more demanding and work-related physical activities (22) which are perhaps not any longer a part of the patient’s life and thereby are not considered influenced by the patient.

Health-related quality of life

The SF-36 results were not pointing in one specific direction. The sample size might have been too small to detect differences in HRQoL since the power analysis calculated 60 participants in each group as a proper figure. This sample size was not possible to reach though within the decided time frame, i.e. inclusion during 3 years. However, when comparing the intervention group with age and gender matched norms, the intervention group had higher baseline scores in some domains from SF-36, see Table 2.

A significant improvement in the intervention group in physical scores of MLHFQ at three months was seen, however, these results were not persistent at 6 and 12 months. Lack of significant result in MLHFQ has also been described by Brubaker and co-workers (42) and according to them one possible explanation was that the participants had good scores in MLHFQ (39.9 points). In our study participants had even better baseline scores in MLHFQ (22.4 points). There is a risk that the most “healthy” patients chose to participate since patients in poor health might not have the energy to join an intervention. Another reason of limited improvement in HRQoL in our study might also be due to the age of the patients. Patients over 65 years have shown, even if having a longstanding illness, to have good HRQoL (43).

A significant improvement in EQ5D-VAS was seen at 3 and 12 months, see Figure 3. EQ5D-VAS measures the patients’ overall experience of HRQoL (32), and is thereby a comprehensive measure where the patient can include the important tasks in their conclusion as opposite to the more detailed questionnaires where every question might not be
of interest or have meaning to the patient. EQ5D-VAS could have a larger relevance to the patients in this older age than a disease specific instrument since many of the patients have other conditions that influence life apart from CHF.

No improvements were seen in anxiety or depression during the intervention. Since the occurrence of anxiety and depression was very low in our study the possibilities for improvement were limited. Low levels of anxiety and depression have also previously been shown in this elderly population (44).

The existing conflicting results between studies of exercise in patients with CHF may be attributed to a variation in adherence rates, training intensity, programme duration and age of the participants. The patients in our study started their exercise at a level of approximately 75% of 1 RM. A limitation of the study is that it is not clear to what extent this workload increased during the exercise intervention programme. If the exercise has not increased it constitutes a lower percent of the 1 RM than the same strain did when the exercise started and the patient was untrained (45). Healthcare professionals need to ensure that the load and volume of exercise is adjusted over time and the patient must continuously evaluate and adapt intensity of exercise to the level appropriate to be able to experience a continuous improvement that spurs new results.

Exercise could be compared to drug therapy; dose and adherence to treatment are crucial for success and it is important to involve the family in improving adherence and to be aware of the patients at especially high risk of non-adherence. It is also critical to understand underlying reasons that prevent patients from participation in exercise training and higher levels of physical activity. According to Scotto (46) the reasons of non-adherence with physical exercise include physical symptoms, low energy, personal beliefs, lack of knowledge and depression, but probably also the perceived use of the gained capacity in ADL and exercise prescription should be designed to meet the unique goals and demands of the patient. Patients need to be told that dyspnoea and fatigue are normal responses during moderate exertion in patients with CHF and this explanation will help to also alleviate anxiety over performing ADL that may provoke shortness of breath. Individualised exercise prescription must be performed through assessment with tests of physical capacity so each patient can receive an individualised programme. Counselling of physical activity levels should be incorporated into patient teaching in which the patients’ responsibility must be enlightened. How lifelong adherence to exercise and sufficient levels of physical activity should be maintained in patients with CHF needs further research.
In physical tests of the upper body one patient improved extremely well and this is partly the reason of very high improvement in Figure 2. However, since the statistics have been conducted with non-parametric tests it has not influenced the significant result.

One limitation was that the study was not randomised. This was due to the impracticability of having intervention programmes at all study sites along with a risk of contamination between groups.

Conclusion
This study shows that endurance and resistance exercise in a combined primary care and home based setting could be used to improve muscle function and walking capacity in elderly patients with CHF. The positive effects raise the abilities to perform a wider range of physical activities in daily life. In these older patients an individual evaluation of possible benefit and important ADL must be performed. As it can be assumed that CHF will be a chronic illness to be managed rather than cured also in the future in an increasing elderly population, every month of life with good skills to perform ADL is of importance. Therefore, primary care must incorporate the knowledge of physical exercise in elderly patients with CHF and educate patients and family in this topic.

Acknowledgement
We would like to thank the participants in the study. Physiotherapists in Halmstad, Jönköping and Linköping for their involvement in the study. This research was financially supported by The Research Council of South-eastern Sweden (FORSS), Scientific Board in the County Council of Halland and FUTURUM- the academy for healthcare, Jönköping County Council.
References


37. SPSS Inc. Chicago, Ill, USA, 2010.


Figure 1. Flow chart describing how patients with CHF were included and followed up in the study.
Table 1. Baseline demographic and clinical characteristics of participants in the study.

<table>
<thead>
<tr>
<th></th>
<th>Intervention n=28</th>
<th>Control n=31</th>
<th>p-value</th>
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<td></td>
<td></td>
</tr>
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<td>27/4</td>
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</tr>
<tr>
<td><strong>Age</strong></td>
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<td>Mean age (SD)</td>
<td>76.2 (7.2)</td>
<td>74.4 (8.6)</td>
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<td>17 (55%)</td>
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<tr>
<td>III</td>
<td>7 (25%)</td>
<td>14 (45%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>8 (29%)</td>
<td>-</td>
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<tr>
<td><strong>Aetiology</strong></td>
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<td>13 (42%)</td>
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<td>Heart infarction</td>
<td>7 (25%)</td>
<td>10 (32%)</td>
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<td>Diabetes</td>
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<td>Primar valvular disorder</td>
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<td>19 (61%)</td>
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<td>23 (74%)</td>
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<td>Warfarin</td>
<td>8 (29%)</td>
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<td>21 (75%)</td>
<td>29 (94%)</td>
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<td>3 (10%)</td>
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<td>Acetylsalicylsyra</td>
<td>14 (50%)</td>
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<tr>
<td>A2 inhibitor</td>
<td>9 (32%)</td>
<td>12 (39%)</td>
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Figure 2. The average difference (Δ%), between intervention and control group in physical fitness.
† p=<0.05 ‡ p=<0.01 †† †† p=<0.001
Figure 3. The average difference (Δ%), between intervention and control group in 6MWT and EQ5D-VAS. † p=<0.05 ‡ p=<0.01
Table 2. Mean and standard deviation of $\Delta$ in measurements of physical capacity, HRQoL, anxiety and depression at 3, 6 and 12 months. In SF-36 age and gender matched norms are received from the HRQL-group in Sweden. $p<0.05$ is considered as significant.

<table>
<thead>
<tr>
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<th>6 months</th>
<th>12 months</th>
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<tr>
<td>PSFS</td>
<td>4.2 (1.9)</td>
<td>4.2 (1.7)</td>
<td>0.982</td>
<td>1.2 (1.7)</td>
</tr>
<tr>
<td>DRI</td>
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<td>35.8 (17.7)</td>
<td>0.873</td>
<td>-3.7 (14.1)</td>
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<tr>
<td><strong>Health-related quality of life</strong></td>
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<tr>
<td>SF-36, PF</td>
<td>60.1</td>
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<tr>
<td>SF-36, RP</td>
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<td>0.521</td>
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<tr>
<td><strong>HADd</strong></td>
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IN: Intervention; CN: control norms; PSFS: patient specific functional scale; DRI: disability rating index. SF-36; PF: physical functioning; RP: role physical; BP: bodily pain; GH: general health; VT: vitality; SF: social functioning; RE: role emotional; MH: mental health; PCS: physical component scale; MCS: mental component scale. MLHFQ: Minnesota living with heart failure questionnaire; EQ5D-VAS: EuroQoL 5D VAS; HADa: hospital anxiety and depression scale, anxiety; HADd: hospital anxiety and depression scale, depression. Notably, in MLWHF lower scores indicate higher HRQoL and lower depression scale, anxiety; HADa, hospital anxiety and depression scale, depression. Norms in SF-36 age and gender matched norms are received from the HRQL-group in Sweden. $p<0.05$ is considered as significant.
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School of Health Sciences Dissertation Series


