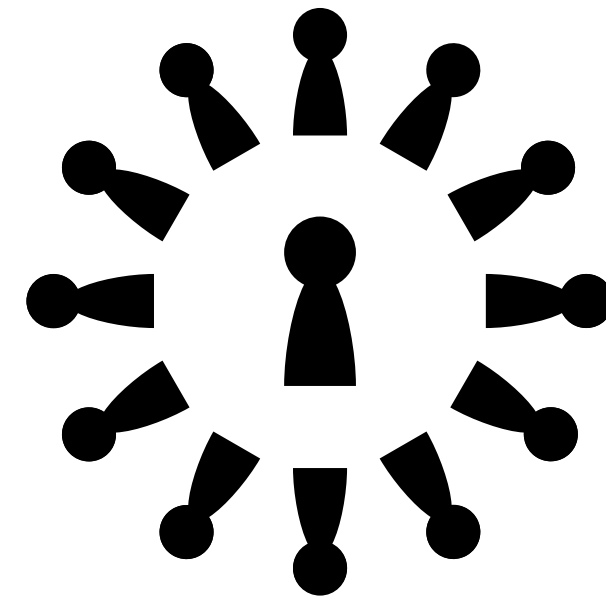


LIVING WITH HEART FAILURE: EFFECTS OF AN EDUCATIONAL PROGRAMME ON PATIENTS AND FAMILY MEMBERS



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ABSTRACT

Chronic heart failure (CHF) is a syndrome with various underlying causes and when an individual is diagnosed with CHF it affects daily life of both him/her and family members. An educational programme may have the capability to increase the knowledge and understanding of family members and improve their possibility to support the patient with CHF.

In **paper I** the aim was to investigate perceived loneliness and social support in 149 patients with CHF and whether there was an association with gender, age, health care utilization and mortality. Loneliness was reported by 20% of the patients, who were younger and more often women. Those who perceived loneliness had fewer social contacts and emotional contacts and were less satisfied with close relationships and available social contacts. Despite not having more severe CHF, those feeling loneliness had more days in hospital and more readmissions during 12 months.

In **paper II and III** 128 family members of patients with CHF were randomly assigned to an intervention group (IG) who received a multi-professional educational programme or to a control group (CG) receiving routine ward information. Family members filled in questionnaires three times during one year. Aim of **paper II** was to investigate if disease-related knowledge increased in family members through the educational programme and if there was an effect on healthcare utilization of the patient with CHF. Findings showed that disease-specific knowledge increased significantly in both groups from baseline and at second measurement and remained at third measurement. Family members in the IG had significantly higher knowledge at second and third measurement compared to family members in the CG. Frequency of readmission or number of days hospitalised during 18 months did not differ between the groups. In **paper III** the primary aim was to investigate if quality of life (QoL), anxiety and depression were affected in family members after attending an educational programme. The secondary aim was to investigate the impact of social support, family and patient related variables and sense of coherence on changes in QoL, anxiety and depression during the study period. Findings showed no significant differences in QoL, anxiety and depression between IG and CG due to the education. Adequacy of social network and baseline measurement of anxiety and depression predicted anxiety and depression at third measurement. Baseline measurement of QoL and family member's age were predictors for QoL at third measurement. Younger family members had higher QoL.

In **paper IV** the aim was to describe family members' experiences of attending an educational programme. Eleven family members were interviewed. Three main categories emerged: "making the disease comprehensible" deals with increased knowledge among family members and thereby attaining greater understanding of the person with CHF; "increasing involvement" comprises family members' self-confidence and ability to become a resource for the ill person; "influencing family members' wellness" deals with the positive experience of meeting others in the same situation and the importance of taking care of themselves. Several of the family members would have preferred to attend the education with the person with CHF.

In conclusion Perceived loneliness in patients with CHF was most common among women and younger persons, and was associated with health care utilization, social network and support. The implemented educational programme for family members of patients with CHF seemed to have a subjectively experienced positive effect. The family members had increased knowledge, confidence and understanding of the disease, which made it easier for them to support the patient in their self-care management. The educational programme did not affect levels of QoL, anxiety and depression in family members nor health care utilization of the patients.

Keywords: Chronic heart failure, social support, educational programme, family members

LIST OF PUBLICATIONS

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

- I. **Löfvenmark C**, Mattiasson A-C, Billing E, Edner M. Perceived loneliness and social support in patient with chronic heart failure. *European Journal of Cardiovascular Nursing* 8 (2009) : 251-258
- II. **Löfvenmark C**, Rydell Karlsson M, Edner M, Billing E, Mattiasson A-C. A group-based multi-professional education programme for family members of patients with chronic heart failure: Effects on knowledge and patients' health care utilization. *Patient Education and Counseling* (2010) In Press
- III. **Löfvenmark C**, Saboonchi F, Edner M, Billing E, Mattiasson A-C, Evaluation of an educational programme for family members of patients living with heart failure. Submitted.
- IV. **Löfvenmark C**, Billing E, Edner M, Mattiasson A-C. Family members' experiences of a group-based multi-professional educational programme about chronic heart failure. (Submitted)

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LIST OF ABBREVIATIONS

AVSI	Availability of Social Integration
ADSI	Adequacy of Social Integration
AVAT	Availability of Attachment
ADAT	Adequacy of Attachment
ACE	Angiotensin Converting Enzyme
ARB	Angiotensin Receptor Blocker
CG	Control Group
CHF	Chronic Heart Failure
EF	Ejection Fraction (function of left ventricular)
ESC	European Society of Cardiology
FM	Family members
HADS	Hospital Anxiety and Depression Scale
HRQL	Health Related Quality of Life
IG	Intervention Group
ISSI	Interview Schedule for Social Interaction
NYHA	New York Heart Association
SOC	Sense of Coherence
QoL	Quality of Life

INTRODUCTION

My interest in this area started with my clinical work as a registered nurse on a ward specialised in care of patients with chronic heart failure (CHF). Through questions from family members I noted that it was rather common that they did not have an understanding of chronic heart failure despite the fact that the patient had been living with chronic heart failure for a long time. Family members did not have knowledge concerning what heart failure was or about the seriousness of the disease. I also noted that family members were affected by the patient's condition and that they did not always know how to relate to the situation. My concern was how to improve the support for family members. A discussion started about the possibility to offer family members information and to provide the chance to meet other family members of patients with chronic heart failure.

When an individual is diagnosed with a serious chronic disease, such as CHF, it affects daily life for both him/her and family members¹⁻⁴. Therefore family members have to adjust their own daily living and might have less time for own activities⁵. CHF is a syndrome with a variety of symptoms, where the most common are dyspnoea and fatigue⁶⁻⁷, and it is the most common cause of hospitalisation in people over 65 years of age⁸. It is a progressive illness with a high mortality rate, and the course of CHF is transient^{6,9}, and therefore unpredictable.

Living with CHF means that the life situation is often changed for the individual with heart failure and he/she needs help to both make changes and adjust to the new life situation according to his/her ability¹⁰. Family members are therefore of great importance for the patients in that they often are in need of the help and support of their family members¹¹. They often need help in daily life activities, e.g. with shopping, paying the bills and housekeeping^{2,4}. Support with disease specific issues such as medication, observing symptoms and providing emotional support and accompanying to the clinic, is also often provided by family members^{2,12}. A spouse's perception of the disease has been shown to be of importance for the patient's recovery, as reported in a study of patients with a first myocardial infarction¹³.

Care of patients with CHF includes medical treatment and self-management. Education and information are important for the patients, for their understanding of their condition, including medical treatment and self-care management¹⁴. Studies suggest that education programmes for patients with CHF have the potential to reduce hospitalisation, increase disease-related knowledge¹⁵⁻¹⁶ and increase quality of life (QoL)¹⁷⁻¹⁹. Further, educational interventions have been shown to improve self-care management as reported in a systematic review²⁰, and decrease health care utilization¹⁹.

Education is important for family members as they are a support for the patient and provide help with daily medication, monitoring symptoms and emotional support and for this they need knowledge. There are only a few studies that have evaluated the effects of educational programmes aimed at family members of patients with CHF. The

design of these educational programmes has been varied and with different outcomes where the family members and patients have participated in the educational programmes together²¹⁻²³.

An educational programme might increase family members' disease-specific knowledge and their possibility to support the patient with CHF. Further, it could be of importance for family members to be able to express themselves without the patient present, and share experiences with other family members of patients with CHF. We therefore conducted an educational programme including only family members.

The empirical part of this thesis is comprised of three studies evaluating the effects of an educational programme for family members. Patients living with chronic heart failure are in need of social support for their daily living and one paper is focusing on social network, social support and perceived loneliness in patients with CHF.

The introductory section is followed by a background providing the context for this thesis, starting with an overview of chronic heart failure and thereafter the different areas to be covered by this thesis which takes into account living with heart failure from the perspectives of the patient with CHF and the family member, need of learning, patient education and family member education.

BACKGROUND

CHRONIC HEART FAILURE OVERVIEW

Definition, aetiology and epidemiology

Heart failure is a syndrome that includes the following features: symptoms of heart failure, such as shortness of breath at rest or during exertion, and/or fatigue; signs of fluid retention such as pulmonary congestion or ankle swelling; and objective evidence of a structural or functional abnormality of the heart at rest ⁶. A clinical response to treatment directed at heart failure is helpful if the diagnosis remains unclear ^{6,8}.

CHF is caused by a variety of underlying reasons, where the most common are ischemia heart disease and hypertension ^{6,24}. CHF can be caused both by systolic and diastolic dysfunction. The systolic dysfunction affects the hearts contractility and diastolic dysfunction affects the filling process of the heart.

In diastolic CHF the systolic function is preserved and this phenomenon is often called HFpEF (Heart Failure with preserved Ejection Fraction) ⁶. HFpEF occurs in 40 percent or more of the cases and it is more common in the elderly and women ²⁵. The prevalence of CHF in the general population is suggested to be 2-3% and it increases with age ^{6,25-26}, and in persons in the 70- to 80-years age range, the prevalence is approximately 10 percent. The mean age of persons with heart failure is 75 years ^{6,27}.

Prognosis and hospitalisation

The prognosis of CHF is poor and the mortality rate is high, despite modern treatment ²⁸⁻²⁹. However, in some countries mortality has been reduced, partly attributable to the availability of modern treatment ³⁰. In elderly patients, >80 years, the overall 5-year mortality rate was found to be 81 percent after first hospital admission and for patients <80 years the 5-year mortality rate was 48 percent ³¹.

CHF is the most common reason for hospitalisation in persons over 65 years ⁸. Five percent of all acute hospitalisations are attributed to CHF, and 40 percent of those who are admitted to hospital for CHF die or are readmitted within one year ⁶. Different causes contributing to the worsening of CHF are non-adherence to treatment, anaemia, infections, arrhythmia, lung disease, thyroid dysfunction, insufficient drug compliance and pulmonary embolism ²⁷. CHF is costly for society and hospital care accounts for the greater part ³²⁻³³. In Sweden the costs constitute approximately two percent of the national health care budget ³⁴⁻³⁵.

Symptoms

There is a wide variety of symptoms in CHF, and the most common symptoms are breathlessness and fatigue ⁶⁻⁷. Patients with CHF have also reported sleep disturbance, ankle oedema, pain, cough and loss of appetite as symptoms ³⁶⁻³⁷.

One common way of classifying functional capacity is by the New York Heart Association functional classification (NYHA-class) which has been proven to be clinically useful ⁶ (Table 1).

Table 1. NYHA functional classification

NYHA-class I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation or dyspnoea
NYHA-class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation or dyspnoea
NYHA-class III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity results in fatigue, palpitation or dyspnoea
NYHA-class IV	Unable to carry out any physical activity without discomfort. Symptoms at rest. If any physical activity is undertaken, discomfort is increased.

Treatment of chronic heart failure

Medical treatment and invasive treatment

Medical treatment of CHF is aimed at reducing mortality and morbidity, such as reduced symptoms and improved quality of life and decreased needs for hospitalisation. Basic pharmacological treatment of CHF includes diuretics, angiotensin converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARB), beta-blockers, and sometimes also aldosterone antagonists and digoxin. Patients should be informed about the indication of the drugs and the doses, and they should also be provided information about the effects and side effects of the drugs ⁶.

When CHF is caused by a surgically correctable condition, surgical treatment is warranted. Coronary artery bypass grafting (CABG) may improve the outcome for some patients with an aetiology of ischemic heart disease. For some patients a valve operation is an option when the cause of CHF is valve disease ³⁸. A cardiac resynchronization therapy pacemaker or cardiac resynchronization therapy with defibrillator function can be an option for patients in NYHA-class III-IV who are symptomatic and have reduced ejection fraction ($EF \leq 35\%$) despite optimal medical treatment. In some, very rare cases, heart transplantation may be indicated ⁶.

Non-pharmacological treatment

Non-pharmacological treatment includes self-care management, adherence to treatment, diet- and exercise recommendations, and self-monitoring of symptoms and signs of CHF, sleep and breathing disorder and psychosocial aspects ^{6,39}. Self-care management aims to improve symptoms, functional capacity, quality of life (QoL), morbidity and prognosis ^{6,39}.

Self-care management

Self-care is defined as the decision-making process the patient uses in the choice of behaviours that maintain physiological stability, i.e. symptom monitoring and treatment adherence, and the response to symptoms when they occur ⁴⁰. Information about signs and symptoms of CHF should be provided to enable recognition of deterioration.

Worsening of CHF often includes an increase in weight and the patient with CHF should be challenged to have control over their weight by regular weight monitoring. In the case of sudden weight gain, they should be informed of the use of flexible diuretic therapy and that they can increase their diuretic dose. There should be advice about sodium and fluid restrictions, with 1½-2 L fluid per day^{6, 14, 39}. Patients with CHF often suffer from thirst, and the importance of fluid restrictions have been discussed⁴¹⁻⁴². It has been shown that clinically stabilised patients with CHF on optimal pharmacological treatment might be allowed to have a more liberal fluid intake⁴². There are no exact guidelines for sodium intake, but avoidance of excessive salt intake should be recommended^{6, 43}. Further, information and recommendation to be immunized against influenza, maintain good glucose control in case of diabetes and to have an understanding of the importance of smoking cessation should be given. Nutritional recommendations also include prevention of malnutrition and weight reduction in the overweight and in obese, and a moderate alcohol intake. To have an understanding of the benefits of performing regular physical training and to be reassured and comfortable with physical activity is important for the patients^{6, 14, 39}. But also the need of taking a rest is important knowledge^{14, 39}. Regular, moderate activity is beneficial for all patients with heart failure in a stable condition⁴⁴⁻⁴⁶. Physical training has had good effects on improving QoL^{6, 44} and reducing morbidity, re-hospitalisation and all cause mortality⁶. Relaxation therapy, including relaxing muscle groups, and exercise training has been shown to be effective in lowering anxiety, reducing dyspnoea and improving overall emotional status⁴⁶.

Compliance and adherence

Studies have shown that patients with CHF often have a low compliance and adherence to treatment^{40, 47-48}. Receiving information about self-care management may lead to improved adherence to treatment^{6, 49}. There have been some studies that have shown that although the patients had received recommendations and information about self-care management such as daily weighing, fluid restrictions, diet and exercise, some of them still had a low adherence to treatment^{36, 48}. Barriers to maintaining self-care as expressed by patients with CHF were lack of self-care education, financial constraints, no perceived benefit in self-monitoring and low self-efficacy. The patients wanted to improve their self-care but needed tools for improvement⁵⁰. Low compliance and adherence to treatment have been shown to be associated with adverse outcome and a higher extent of health care utilization such as hospitalisation^{14, 48, 51}. In a study by Ekman et al.⁵² the patients were found to have a high adherence to medical treatment during the study period of 58 months. The high adherence might be explained in that the patients had regular contact with nurses and physicians who monitored the patient's medication and followed their health problems as well as the patient's belief in the medication.

LIVING WITH CHRONIC HEART FAILURE

Defining chronic illness is complex since individuals experience and adjust to their illness in different ways. One definition has been formulated by Curtin and Lubkin in 1995 that takes the nursing perspective into account. *Chronic illness is the irreversible presence of, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability* in Larsen^{53, pp 6}. The most important issue is how the patient and family members experience the illness and how they are affected⁵³.

Living with CHF means living with a variety of symptoms such as fatigue, dyspnoea, dizziness, cough and swollenness³⁷, which influence their everyday lives⁵⁴. Fatigue leads to a feeling of tiredness, impaired functioning, difficulties in concentrating and reduced motivation⁷, and is often accompanied by weakness and unpredictable variations in physical ability⁵⁴. Living with CHF also means living in fear of pain, death and for what may come in the future⁵⁴. It can also give a feeling of being captured in their own bodies and that they had to give up things they were previously able to do^{10, 55-56}, which could create a feeling of being a burden to others^{55, 57-58}.

Impact on quality of life, depression and anxiety

WHO⁵⁹ has defined quality of life (QoL) as an *individuals' perceptions 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*. The perception of QoL is different in different people depending on their context⁶⁰. Previous research has shown that QoL is affected in patients with CHF⁶¹⁻⁶³ as well as health-related of life (HRQL) has been shown to be affected⁶⁴⁻⁶⁶ where HRQL was lower in an elderly group of patients compared to a healthy control group of the same age. The patients especially reported physical dimensions as low⁶⁵. Pihl et al. 2010⁴ found that some patients with CHF were striving to retain their quality of daily life and that they accepted their own lowered capacity.

Depression and anxiety are common in patients living with CHF⁶⁷⁻⁷⁰. It has been shown that patients with CHF have a higher level of depression and anxiety than reported in a healthy population⁶⁷. Depression has been found to be related to NYHA-class, i.e. the worse the functional status the greater the level of depression⁶¹. Quality of life has been shown to be influenced by levels of depression and anxiety⁶⁷.

Importance of social network and social support

Social network and social support can be expressed from two different aspects; first the actual number of persons that are available and what these provide for the person. Second is the perceived adequacy of the individual. A person might have a high level of available persons but still report it as inadequate and vice versa⁷¹. Need of connection and engagement in social relationships is essential to human beings⁷². Both women and men with CHF have expressed that having someone to turn to is positive and create a sense of security⁵⁷ and a feeling of having involvement from the environment⁷³. Patients with a high level of social support have been found to report better overall self-

care in a study by Gallagher et al.⁷⁴. When living with cardiac disease, social relations have been shown to have a health-protective effect⁷⁵⁻⁷⁷, and lack of social support has been reported to be a strong predictor of hospital readmission and mortality, especially lack of social support from spouses⁷⁸⁻⁸⁰. A high quality of married life is a positive predictor for survival for patients living with CHF, and this correlation is stronger in women than in men⁸¹⁻⁸².

Perceived loneliness

Loneliness is defined as a subjective emotional state to be distinguished from the objective states of social isolation and aloneness and is thought to develop when the quality of a relationship does not meet one's need for attachment⁸³. There can be two types of loneliness; social loneliness and emotional loneliness and they can occur together or independently⁸⁴. In this thesis we measured *perceived loneliness*, however what patient reports is a *feeling of loneliness*, why these two terminologies will appear throughout. Feeling of loneliness is not always the same as being alone, as a person can have a small network and not feeling lonely or vice versa⁸³.

Loneliness has been reported to be associated with an increased risk for heart disease in an older group of individuals with a middle age of 70 years⁸⁵. Social isolation has been shown to be associated with increased risk for mortality in patients with CHF both in the short term (24 months)⁷⁹ and in the long term (six years)⁸⁶, and is an independent risk factor for coronary heart disease in both women and men and in different age groups, as reviewed by Bunker et al.⁸⁷.

LIVING WITH SOMEONE WITH CHRONIC HEART FAILURE

There have been several definitions of family members. Wright and Leahey^{88, pp 50} have stated a definition of family as: *family is how they say they are*. Therefore a family member might be a spouse, children, other relatives or friends who feel that they have a close relation with the ill person⁸⁹.

The definition of family member in this thesis is someone the patient is living with or otherwise someone else the patients chose as family member.

Impact in daily life

When a person is diagnosed with heart failure also family members are affected both physically, emotionally and socially^{1, 3-4}. Family members sometimes feel isolated due to the illness and the impact on the relationship caused by CHF such that they could not do things together as they did before². When living with someone with CHF, daily life is limited⁹⁰ by daily medication the patient has to take (e.g. diuretics)³, the patient's possible fear of being left alone³ and by physical limitations caused by CHF⁴.

Previous research has shown that family members often provide care to the patient such as providing medication, observing symptoms and providing emotional support^{2, 5, 12}.

They also sometimes have to make the decision about seeking care for the patient³⁷.

Research has shown that when the patient is affected by fatigue and physical limitations due to the illness family members have to take responsibility for practical matters^{2, 4, 90} in daily life and activities⁴. The course of CHF has been described by family members

as living day-to-day, where some days the patient's condition is improving and other days he/she wakes up and can hardly breathe². Therefore making plans for the future is difficult due to the changeable nature of CHF⁴.

In a study by Pihl et al.⁴ family members expressed that they worried about the ill person's physical condition and also about the effects on their own life. It caused anxiety to not know what physical strain the patient could handle. The most burdensome effect on their own life was the limited social interaction and their decreased personal freedom and less time for activities with friends^{5,91}. It has also been shown that some spouses feel caregiver burden^{12,91}, and in one study it was found that women feel more caregiver burden than men¹².

Effects on quality of life, anxiety and depression

Caring for someone with a serious disease has an impact on the family members' QoL⁶³. Quality of life has been found to be low in spouses of patients with CHF, lower than in the general population⁶³ and low well-being⁹², and female spouses have lower QoL than male spouses^{62,93}. The physical dimensions were found to be low for family members of patients with CHF while the mental dimension was not so low⁶¹.

It has also been found that level of anxiety and depression are higher in spouses of patients with CHF compared to a general population⁶⁷, and some studies have shown that the spouse has the same level of anxiety and depression as the patient^{67,94}. However, this has not been shown in all studies. In a study by Mårtensson et al.⁶¹ the patients had more depression than their spouses.

Need of information and social support

When living with someone with a serious disease it is of great importance to receive social support from others, such as children, neighbours and friends²⁻³. Having help with daily chores gives the spouses of the ill person more time and energy to visit the ill person in the hospital and to give support to the patient. It is mostly the children of the spouses that provide help with daily chores³. Previous studies have shown that having someone to talk with contributed to a feeling of security and not being alone²⁻³, and to be able to share experiences with someone in the same situation was seen as most helpful because they had a genuine understanding of the situation³. Family members felt that talking to others helped them to deal with CHF².

Lacking information is stressful for both the individual with CHF and family members⁹⁵, and causes worries⁴. Family members have expressed that having a possibility to talk with health care professionals and being offered information was of great importance and relief for family members³. Receiving information and education made family members more prepared to have discussions with the individual with CHF³. In a study by Imes et al.², family members described that lack of information created frustration. When they received information it was often given in a way that they did not understand, because health care professionals used a professional jargon when delivering information. Family members wanted more information about how to treat

symptoms, where to find more information about CHF and how CHF progresses as an illness and what to expect for the future. Family members have experienced that they are invisible to the health care professionals ⁴.

EDUCATION

Need of learning

The goal of education for patients and family members aims to help to develop decision-making skills, gain survival skills and learn how to recognise problems and respond appropriately ⁹⁶. Further, the education and learning can create a feeling of security, self-control, trust and participation for the individual. To enable a feeling of self-control and security in ill persons and their family members' knowledge is of importance. Knowledge is one of the keystones so that the patient and family members can adjust to life style changes caused by the disease and treatment, and thereby maintain or improve health and quality of life ⁹⁷. Knowledge itself does not always link to behavioural change; it should be combined with self-efficacy and skills, and an understanding of the illness is also of importance ⁹⁶.

The definition of education emphasizes a change in behaviour, and includes information about the purpose for changing the behaviour ⁹⁸. According to Marton and Booth ⁹⁹ education has the purpose to change something in another being, which might result in that the person who has been educated can see his/her environment in a different way. Information is a concept of transition of knowledge where there are no rules to control if the recipient has received and understood the information ⁹⁸.

Didactic

The word didactic can be translated in both an active way, i.e. to teach, and a passive way, i.e. to learn. The didactic has some fundamental questions, particularly "what to learn", "how to learn" and "why to learn", but also gives answer to "who is to learn", "when to learn", "with whom to learn" and "where to learn" ¹⁰⁰. The person designing a programme/education has a goal with the education and will design the programme thereafter, but also the participants influence the programme, especially if they participate in an active way ¹⁰⁰.

Adult learning theory

Theories of adult learning started to be applied at the beginning of the 1970s and the best known is the andragogy model by Knowles. Andragogy has been defined as *the art and sciences of helping adults learn* ¹⁰¹. Theories about adult learning give an understanding to how the adult learns ¹⁰². The learning for adults is considered to be different from youths since they have acquired life-experiences. Malcolm Knowles ¹⁰³ wrote his first book about adult learning in 1973. Knowles pointed out five key assumptions about adult learning: adult learners are motivated to learn as they experience needs and interest in what that learning will satisfy, the adult's orientation to learning is life-centred, experience is the richest resource for the adult's learning, adults

have a deep need to be self-directing and individual differences among people increase with age.

The andragogical model is based on five assumptions:

The need to know: adults need to know why they need to learn something before undertaking it. If they do so they will invest more energy to learn. *The learner's self-concept:* adults have a self-concept of being responsible for their own life and making their own decisions, and they want to be seen and treated by others as being capable of self-direction. *The role of learners' experiences:* the adult has acquired both a greater volume and a different kind of experience compared to youths, just by having lived longer. But they do also have different kinds of experiences. *Readiness to learn:* adults become ready to learn those things they need to know and to be able to do in order to cope effectively with their real life situation. *Orientation to learn:* adults are life-centred in their orientation to learn. They are motivated to learn something when they perceive that it will help them perform tasks or deal with problems that they are confronted with in their life situation ¹⁰³.

Patient education

Patient education has been defined as the process of influencing behaviour and producing the changes in knowledge, attitudes and skills necessary to maintain or improve health ⁹⁶.

Since 1990 education for patients living with CHF has been given through nurse-led heart failure in most clinics in Swedish hospitals with specially trained nurses. The nurses at the clinics are involved in follow-up, drug titration and patient education about self-management ¹⁰⁴. The nurse-led heart failure clinics have shown that good improvement in self-care behaviour, reduced readmissions and days at hospital and improved survival ¹⁰⁵.

There are evaluations of educational interventions for patients with CHF with different designs, e.g. computer based education, nurse-based management programme, nurse-directed education and intervention programme including patient education consultation with a cardiologist and monitoring in heart failure unit ¹⁵⁻¹⁸. Follow-up periods have varied including 6 months ¹⁵⁻¹⁶, 9 months ¹⁷, 12 months ¹⁸. The effect of these educational programmes for patients with CHF has shown that patients increased knowledge ¹⁵⁻¹⁶, improved QoL ¹⁷⁻¹⁸ and reduced health care utilization ¹⁸.

The effects of different educational interventions have been evaluated in several systematic literature reviews. A meta-analysis by Jovicic ¹⁰⁶ included six studies with the aim to evaluate the effectiveness of self-management interventions on hospital readmissions and mortality and health related QoL. Jovicic concluded in the meta-analysis that self-management programmes for patients with CHF decreased hospital readmission, both all-cause and CHF –related. Furthermore, some interventions were also shown to be cost-effective. None of the studies had any effect on patients' health related QoL or mortality. The included studies were published during the period of 1998-2005.

A literature review by Yu ¹⁰⁷ during the period of 1995-2004 included 21 studies. The aim was to identify the characteristics of disease management programmes which were essential to reduce hospital readmission and/or mortality of older people with heart failure. In four studies mortality was reduced and in eleven studies readmission was decreased. Several studies showed improved QoL in the patients. It was found that effective management programmes to a higher extent followed the European Society of Cardiology (ESC) guidelines ⁶ and were more often conducted by a specialist team. An effective disease management programme should include both exercise training and psychosocial care. Furthermore, a cardiac nurse and cardiologist should be actively involved and a flexible approach to follow-up care should be adopted.

Boyd ²⁰ performed a systematic literature review with the aim to review educational interventions that have been implemented for heart failure patients and assess their effectiveness. A total of 19 studies were included in the review, published between 1998 and 2008, with varying outcomes assessed. In eight of these studies it was found that patients' knowledge increased, eight evaluated self-care which was improved in six of the studies, where only one assessed self-care with the patients weighing themselves. Four studies of 14 reported decreased readmission and three reported significantly decreased mortality. Only two studies of 12 reported increased QoL in the patients. There was a range of designs, and the most common was one-on-one didactic patient education. Boyd concluded that patient education is important for the quality of the CHF management, but it is difficult to establish which educational strategy is the most effective since the interventions varied in delivery methods and duration as well as that there were different outcomes available to evaluate the education.

Family member education today

It is recommended to invite family members to educational programmes ^{6, 108}, since it has been reported that sufficient support improves the patient's adherence to treatment ⁷⁴. According to Bergh ⁸⁹, family members today and in the future are expected to take more responsibility for the aftercare of their ill relative. To receive information at an early stage in the patient's disease process can ease their situation. It has been shown that family members are not always involved in the patient's education at nurse-based clinics. It is of importance that family members receive the same information as the patient to be able to take part in the treatment and improve the social support for the patient ¹⁰⁴.

Educational interventions for family members of patients with other diagnoses, such as stroke and cancer have been shown to improve the family functioning ¹⁰⁹, improve disease-related knowledge and reported great satisfaction with an education programme in family members of stroke patients ¹¹⁰. Furthermore, there was a decrease in distress among family members of cancer patients ¹¹¹.

There are few studies that have evaluated the effects of education programmes given to family members of patients with CHF ¹¹². However, there are some studies that have evaluated education and interventions provided to family members of patients with

CHF, where the family members and patient received the educational programme together as described below²¹⁻²².

A study by Dunbar et al.²² evaluated the effects of a family-focused intervention with the aim to promote adherence to dietary sodium restriction. Patients with CHF and a family member were randomised to an intervention group or a control group. The dyads who were randomised to the control group received in-depth educational counselling by a nurse and a dietician. Those who were randomised to the intervention group also received the in-depth education counselling, and further two sessions focusing on enhancing family support and patient choice through communication and empathy. It was found that the adherence to sodium intake restriction increased in the family focused intervention. Disease specific knowledge increased in both the intervention group and the control group. Clark and colleagues¹¹³ have previously performed a family partnership intervention, where the family member session focused on giving non-evaluative feedback, encouraging the patients' responsibility and self-initiation, showing understanding and empathy and to promote the patients' self-confidence in the self-management behaviour. The findings showed it to be a good approach in that family members were helping the patient to manage the disease.

Duhamel et al.²¹ evaluated the effects of a family nursing intervention from the family member's perspective with a qualitative approach. One of the aims was to explore the couple's perceptions of the impact of a family nursing intervention. Four couples were interviewed after attending the programme, where the couples met a nurse during four therapeutic meetings. It was found that disease-related knowledge increased and the couples had a better understanding about each other's experiences of the illness. The increased knowledge promoted greater compliance to treatment and more confidence in managing self-care.

In a thesis by Ågren²³, an evaluation of the effects of an integrated dyads programme with education and psychosocial support to patients with CHF and their partner was performed. The couples in the control group received care as usual. In the experimental group the patients received usual care and in addition the couples participated in an integrated intervention including psychosocial support, knowledge about CHF and perceived control to reduce stress and caregiver burden. The intervention was delivered through nurse-led face-to-face counselling, by a computer based CD-ROM programme and written teaching material. After a follow-up time of 3 months, patients in the experimental group had significantly higher perceived control than patients in the control group. The partners' perceived control was unchanged. There were no differences in HRQL, or symptoms of depression between the groups.

In summary the design and the methods of the educational interventions, where family members and patients participated together, have varied and different outcomes were available to evaluate the interventions.

RATIONALE

Previous research has shown that social network and social support are of importance for the prognosis in patients with chronic heart failure, and perceived loneliness is a predictor for hospitalisation for patients with chronic illness. The impact of perceived loneliness in patients with chronic heart failure has not been investigated to our knowledge.

In the literature it has been shown that family members of patients with chronic heart failure often lack information from health care professionals about the disease process of the patients and sometimes feel unseen by health care professionals. To be a more effective resource for the patients and to be able to discuss different aspects of the disease, such information is important.

Education of patients with chronic heart failure has shown improvements in health care utilization, self-care management, adherence to treatment and quality of life. Further, educational programmes for family members of patients with other diagnoses have shown improvements in distress, disease related knowledge and an overall satisfaction with design and content of the programme.

Educational programmes for family members of patients with chronic heart failure have been evaluated but these educational programmes have been given with both the family member and the patient present. The evaluations have shown improvements in disease-specific knowledge and understanding of the patient's illness and adherence to sodium intake restrictions. Sharing individual experiences with others in the same situation is of great value, in that they have a genuine understanding for their situation. To our knowledge no previous educational programme has been offered exclusively to family members of patients with chronic heart failure.

AIMS OF THE THESIS

Overall aim

The overall aim of this thesis was to achieve an understanding of the effects of a group-based multi-professional educational programme for family members of patients with chronic heart failure and to investigate social network, social support and perceived loneliness in patients with chronic heart failure.

Specific aims

Paper I

The aim was to investigate perceived loneliness and social support in patients with chronic heart failure. Further, to investigate whether loneliness and social support might be associated with gender, age, health care utilization and mortality.

Paper II

The aim was to investigate if family members of patients with chronic heart failure increased knowledge about chronic heart failure through a group-based multi-professional educational programme and whether there was an effect on patients' health care utilization.

Paper III

The primary aim was to investigate if quality of life, levels of anxiety and depression were affected in family members of patients with chronic heart failure after participating in a group-based multi-professional educational programme. The secondary aim was to investigate the impact of social support, family and patient related variables and sense of coherence on changes in quality of life, anxiety and depression during the study period.

Paper IV

The aim was to describe how family members of persons with chronic heart failure experienced a group-based multi-professional educational programme.

METHODS

Table 2. Overview of paper I-IV

	Paper I	Paper II	Paper III	Paper IV
Title	Perceived loneliness and social support in patient with chronic heart failure	A group-based multi-professional education programme for family members of patients with chronic heart failure: Effects on knowledge and patients' health care utilization	Evaluation of an education programme delivered to family members of patients living with heart failure	Family members' experiences of attending a group-based multi-professional educational programme about chronic heart failure
Design	Cross-sectional design with a prospective follow-up	Randomised controlled trial	Randomised controlled trial	Qualitative design and descriptive evaluation
Participants /informants	149 patients with CHF	128 FM of patients with CHF	128 FM of patients with CHF	Interviews: 11 FM Self-reported evaluation: 53 FM
Inclusion criteria	Patients diagnosed with CHF, hospitalised at least once during a 4-month period	FM ≥ 18 years of patient with CHF treated in hospital	FM ≥ 18 years of patient with CHF treated in hospital	Interview: FM who participated in educational programme 5-6 sessions Self-reported evaluation: All FMs who participated in the educational programme
Age mean (SD)	76 (± 10.3)	FM: 65 (± 12.6) Patients: 77 (± 10.3)	FM: 65 (± 12.6)	FM interviewed 58 (38-80)
Age MD (range)				
Data collection	Questionnaires: ISSI, Feeling of loneliness	Questionnaires: Heart failure knowledge	Questionnaires: HADS, Cantril Ladder of Life, ISSI, SOC, SWED-QUAL	Qualitative Interview Evaluation of the programme, structure and content
Data	Patients health care utilization Clinical and demographic data	Patients health care utilization Demographic and clinical data	Demographic data	
Analysis	Statistical methods	Statistical methods	Statistical methods	Qualitative content analysis

FM=Family Members, ISSI= Interview Schedule for Social Interaction, HADS=Hospital Anxiety and Depression Scale, SOC=Sense of Coherence

PARTICIPANTS AND PROCEDURE

Paper I Cross-sectional study with a prospective follow-up

Participants

Patients diagnosed with CHF as first, second or third diagnosis were identified in a diagnosis register at a university hospital within the Stockholm area, who had been hospitalised at least once during a 4 month period. A total of 311 patients were identified. Questionnaires were sent to 213 eligible patients after excluding those with cognitive dysfunction, no previous echocardiography, drug abuse and language difficulties. The final sample included 149 patients, 71 females and 78 males.

Procedure

Written information about the study together with the study questionnaires were sent to the patients and they were also asked to give written approval to collect demographic data from their medical records. Telephone contact was then made with the patients who had not returned the questionnaires after one reminder. The questionnaires were filled out during a telephone interview if the patient consented orally to the study. Of the total sample of 149 patients, 20 were filled out by telephone interview. Health care utilization of the patients, assessed by frequency of readmissions to hospital and numbers of days in hospital, was followed during one year, prospectively from the time of hospitalisation during the 4-month period.

Paper II and III Randomised controlled trial

Participants

Family members of in-patients with CHF who were hospitalised at a hospital in the Stockholm area during 2004-2006, were invited to participate in the study. Inclusion criteria were family members aged ≥ 18 years of patients with CHF who had been treated in hospital. Exclusion criteria were patients with planned heart operation or other serious disease (e.g. cancer, dementia disease and renal failure), no previous echocardiography, living in a nursing home, cognitive dysfunction, drug or alcohol abuse, language difficulties, participating in other studies or if the family members had own serious medical problems.

A total of 1571 patients with CHF were screened, whereof 1065 patients did not meet the inclusion criteria, 174 declined to have a family member participate and 39 were excluded due to other reasons. Thus 293 family members were asked to participate in the study, whereof 157 declined participation and eight family members were unable to be reached.

The final sample consisted of 128 family members, of whom 99 (77%) were women. Seventy-three (57%) were married/living together with the patient and 39 (31%) were children of a patient. Overall 95 (72%) of the family members had an education ≥ 12 years. There were no statistical differences between the groups.

Of the patients, 71 (55%) were men in the total sample. There were no statistical differences between the groups with regard to age, gender, previous history of disease, duration of CHF, EF, NYHA-classification or medication.

Procedure

Information about the study was sent to the patients after discharge from the hospital. After approximately two weeks, the patients were contacted for approval to invite a family member to participate and for acceptance to collect demographic data and data on health care utilization. If the patient gave their approval to ask a family member, information about the study was then sent to the family member.

After the family member had accepted participation, a time was set for a first individual meeting (baseline) where further oral information about the study was given by the research nurse. The participants filled-out baseline questionnaires, and were thereafter randomly assigned to an intervention-group (IG), who received a multi-professional education programme (65 participants) or to a control-group (CG) (63 participants) who received information according to the routines hospital practice. An informed consent was signed to acknowledge participation and to assure the participants' confidentiality in the IG, i.e. not to reveal the identity of other participants and not to reveal private aspects that may arise in the educational sessions. The family members were randomised in blocks of 16. The mean time to gather a block of 16 was four months.

Questionnaires were filled-out three times during one year by both participants in the IG and in the CG to evaluate the intervention: at baseline, after 6 months and after 12 months. Health care utilization, assessed by frequency of readmissions to hospital and number of days in hospital, of the patient with CHF was followed during 18 months in paper II.

Participants in the intervention group were offered a multi-professional educational programme described below. Participants in the CG received information during the hospitalization according to the routine hospital practice. Information was usually provided by a physician or a nurse following a request from a family member. Information could also be provided if the health care providers considered it important for different reasons. Information about CHF was available through a poster and brochures on the ward.

Intervention

Multi-professional educational programme

The didactic has some fundamental questions, particularly "what to learn", "how to learn" and "why to learn"¹⁰⁰. The guiding principle driving the education programme was: what to teach, how to teach and way to teach or in what purpose to teach¹⁰⁰.

What to teach was based on guidelines, from the ESC guidelines⁶ for recommended essential topics in patient education such as understanding the cause of heart failure, symptoms and signs of CHF, pharmacological treatment, risk factor modification, diet

recommendation, exercise recommendation, immunization, sleep and breathing disorders, adherence, psychosocial aspects and prognosis. *How to teach* was by face-to-face education sessions in groups with other family members, and thereby providing an opportunity for family members to meet others to share experiences and to provide a setting for discussions. The group size in our educational programme was eight persons, which is approximately the same size of groups as found in other studies^{110, 114-115}. An intention of our educational programme was to give family members an opportunity to meet others in the same situation, so they could exchange and share experiences. To have the opportunity to discuss how it is to live/be near someone diagnosed with CHF, and discuss problems that arise. Our intention was also to evaluate if QoL, anxiety and depression were affected by the educational programme. Further, to strengthen family members in their support of the patients and thereby effects patients health care utilization.

The multi-professional educational programme, included the following professions: cardiologist, specialist nurse in heart failure, dietician, physiotherapist and a medical social worker. A coordinator (CL) organised the groups and attended at all sessions. The different themes were: medical aspects, self-care, nutrition, physical activities and psychosocial aspects. The programme included six two-hour sessions during six months, and started at 5 pm. There were eight participants in each group and the meetings took place in a conference room at the hospital. Each session comprised one theme with one of the professions. The sessions started with information about the theme for the day, and there was always time available for questions, reflections, discussions and talk about own experiences. During the final session there was time for a follow-up discussion, and there was also a possibility to invite a speaker from one of the previous sessions. To preserve the interaction within the groups, no new participants were included into already started groups.

Paper IV Qualitative design and descriptive evaluation

Informants

Interviews

Family members who had participated in the multi-professional education program five to six sessions out of six possible sessions were asked to participate in an interview study. Eleven family members were included, 10 women and one man. The family members were asked to participate one year after completing the programme. Four of the informants were living together with their ill family member, five were children of a patient, and one was a sister of the ill person and one was a relative that the ill person had chosen as family member.

Information about the study was given in writing and orally. The interviewer and the participant agreed upon a time and place for the interview by a telephone call. Six interviews took place at a meeting room at the hospital, four in a room at the interviewer's place of work and one interview was performed at the respondent's home. The interviews lasted between 40 and 75 minutes, and were tape-recorded with

participants' permission. One pilot interview was performed with the same inclusion criteria and the interview was considered as good and therefore included in the sample.

Self-reported questionnaire

An self-reported evaluation, developed for the study, was filled in after completing the multi-professional educational programme. The evaluation form was given to the family members at the last session and they were asked to fill-in the form nameless and to send back within two weeks. Altogether 53 (81%) participants completed the evaluation form.

DATA COLLECTION

Questionnaires

Feeling of loneliness (paper I)

Loneliness was measured by one single-item question: "Does it happen that you experience loneliness?" with four response alternative "Yes always", "Yes often", "No seldom" and "No never". The response alternatives were later dichotomised into "Yes" and "No" in the analysis process.

A single-item question to measure loneliness has been used in other studies ¹¹⁶⁻¹¹⁹.

Interview Schedule for Social interaction (ISSI) (paper I and III)

To measure social support ISSI was used. The questionnaire has been translated into a Swedish version and modified by Undén et al. ¹²⁰ from the Australian questionnaire developed by Henderson et al. ⁷¹. The instrument has been tested for validity and reliability in Sweden ¹²⁰.

The questionnaire consists of four subscales:

Availability of social integration (AVSI) indicates number of people available for social support (score 0-6). Adequacy of social integration (ADSI) measures the satisfaction with social integration (score 0-8). Availability of attachment (AVAT) indicates perceived occurrence of emotional contacts (score 0-6). Adequacy of attachment (ADAT) measures satisfaction with attachments, defined as close/intimate affectional relationships (score 0-10). A higher score indicates a high level of availability and adequacy of social integration and attachment.

Heart failure knowledge questionnaire (paper II)

The questionnaire measures disease specific knowledge and includes 19 questions and statements with fixed response alternatives. Possible score is 0-19, where higher score indicates better knowledge.

The questionnaire was originally developed for patients with CHF by Rydell Karlsson et al. ¹⁵, and these questions have been revised to be applicable to family members. The questions were revised by exchanging "you" to "a person with heart failure". For example "Are you allowed to drink unlimited?" was changed to "Is a person with heart failure allowed to drink unlimited?".

Three experts, including a nurse in cardiology, a professor of nursing and a cardiologist, reviewed the changes, according Polit and Beck ¹²¹. The questionnaire was modified according to the experts' proposal concerning wording to clarify some of the questions. The Heart Failure Knowledge questionnaire was tested on 19 family members (not included in the study) and no changes were made.

The original instrument has been tested for validity and reliability in patients with CHF¹⁵. In paper II the internal consistency reliability was 0.83 measured by Chronbach's α -coefficient for the revised questionnaire.

Cantril Ladder of Life (paper III)

To measure generic quality of life (QoL) the Cantril Ladder of Life ¹²² was used. This measures QoL on a 10 grade scale, where one is considered as worst possible QoL and 10 is considered as best possible QoL. The question that is asked is "This is a figure that images the ladder of life. Where do you feel you are right now?"

The measurement has earlier been used in family members of persons with CHF ⁶²⁻⁶³.

Hospital Anxiety and Depression Scale (HADS) (paper III)

To measure anxiety and depression the HADS ¹²³ was used. The questionnaire consists of 14 questions: seven items measuring anxiety and seven items measuring depression. Each item is rated on a 4-point Lickert scale (0-3), and each subscale has a total range of 0-21, where 0 is no anxiety or depression. A score of 7/8 or less is recommended for both scales for non-cases of anxiety or depression ¹²³.

HADS has earlier been tested in large non-clinical sample ¹²⁴⁻¹²⁵ which showed that the instrument is valid in a general adult population.

Sense of Coherence (SOC) (paper III)

The sense of coherence scale (SOC) developed by Antonovsky ¹²⁶ measures an individual's coping ability and has been translated to Swedish by Langius et al. ¹²⁷. The short version was used, which consists of 13 questions measuring three dimensions: comprehensibility, manageability and meaningfulness ¹²⁸. The dimensions together measure the concept "Sense of Coherence". Individuals with a strong SOC adopt attitudes that facilitate successful coping with the complex stressors confronting us in the course of living. It has been found to correlate negatively with anxiety ¹²⁷⁻¹²⁹ and depression ¹²⁹⁻¹³¹, and correlate with QoL, i.e. the stronger the SOC the better the QoL ¹³¹. Each question has a scale numbered from 1 to 7 where the participant chooses the numbers that best represent their state. The total possible score is 13-91, and the higher score the higher the sense of coherence. The reliability and validity of the short version has been tested in several studies ^{128, 132}.

SWED-QUAL (paper III)

SWED-QUAL is a Health Related Quality of Life Measurement (HRQL), and has been adapted by Brorsson ¹³³ from measures used in the Medical Outcomes Study (MOS) ¹³⁴⁻¹³⁵. It consists of 67 items and measures 2 single-item and 11 multi-item scales; physical functioning, satisfaction with physical functioning, pain, role limitations because of physical health and because of emotional health, emotional well-being,

cognitive functioning, quality of sleep, general health perception, satisfaction with family life, relation with partner and sexual functioning. The score for the scales is 0 to 100 for each scale, where 0 is lowest possible and 100 highest possible of the different aspects of HRQL.

In this study, six of the subscales have been used: role limitations because of emotional health, emotional well-being, quality of sleep, general health perception, satisfaction with family life and relationship with partner. However, the family members did fill in all of the subscales of the questionnaire. The questionnaire has been used in a Swedish population and showed good reliability and validity¹³³.

Evaluation of the educational programme (paper IV)

A self-reported evaluation was developed to evaluate the structure and content of the educational programme. The self-reported evaluation consisted of 21 questions with fixed response alternatives, such as excellent, good, rather good, bad and very bad. An open question for participants' comments in relation to each question was included. The following aspects were included: structure of the programme (6 questions), content of the programme (6 questions), participant's view about attending the programme in a group with or without the ill person present (4 questions), expectations of the programme (3 questions), and usefulness (2 questions) (Appendix).

Qualitative interview (paper IV)

The interviews were carried out through semi-structured qualitative interviews. An interview guide was used in order to achieve as broad a description as possible of family members' experiences. The interview guide lists the issues to be explored in the interview and to ensure that the same basic topics of inquiry are pursued in all the interviews¹³⁶. Each interview was commenced by asking "*Can you please tell me about your experiences and about knowledge you have gained by attending the programme?*", giving the informants the opportunity to speak freely about their experiences.

The informants were asked to describe their experiences in relation to following: Knowledge in relation to the different themes.

If their own lifestyle in any way was affected by attending the programme.

If in any way new questions emerged by attending the programme.

If attending the programme in any way created fear or insecurity.

As a first step in the data collection a pilot interview, with the same inclusion criteria, was carried out in order to evaluate the interview guide and to determine the length of the interview. Consequently there were no revisions of the interview guide and the pilot interview was considered as good and was therefore included in the study¹³⁷.

Demographic data, clinical characteristics and health care utilization

Demographic data of the patients in paper I-III were collected from medical records. In paper I the patient filled in a form developed for the study to capture demographic data, i.e. age, sex, social status, having children and education level. Health care utilization in paper I was collected from a register at the hospital, and mortality was requested from The Swedish National Board of Health and Welfare. In paper II-III health care utilization and mortality were requested from The Swedish National Board of Health and Welfare. Demographic data of the family members in paper II and III were collected using a form developed for the study.

ANALYSIS METHODS

Table 3. Overview of analysis methods in paper I-IV

	Paper I	Paper II	Paper III	Paper IV
ANOVA/ANCOVA		X	X	
Chi-square test/Fisher's exact test	X	X		
Descriptive statistics	X	X	X	X
Hierarchical linear regression			X	
Kaplan-Meyer		X		
Logistic regression	X			
Mann-Whitney U-test	X	X		
Qualitative content analysis				X

The statistical analyses were conducted with SPSS for Windows (Chicago, Illinois).

Descriptive statistics were used in all papers and are presented by mean, standard deviation, range, numbers and percent. Non-parametric data were evaluated by Chi-square test, or Fisher's exact test in case of small expected frequencies. Chi-square was used to evaluate the loneliness question (I) and categorical variables, such as demographic data on family members and patients and clinical characteristics of the patients (I and II). A logistic regression analysis was performed to find predictors for feeling of loneliness (I). The independent variables that were included in the multivariate logistic regression were: subscales from The Interview Schedule for Social Interaction, gender, age over or under 65 years, having children, living situation, civil status, education level, duration of heart failure, CABG, pacemaker, NYHA-classification, ECG, EF, ischemic heart disease, arterial fibrillation and creatinine. Mann-Whitney U-test was used to examine differences in Interview Schedule for Social Interaction (I) and health care utilization, i.e. frequency of re-admissions and number of days in hospital, since these were not normally distributed (I and II). First re-admission between the groups was analysed by the Kaplan-Meyer method, also cases of mortality were included in this analysis (II).

Analysis of variance, ANOVA, was used to examine differences between group means with regard to the Heart Failure Knowledge questionnaire. Significant differences were further examined with post-hoc test by Tukey (II).

To examine the effect of the intervention in paper III, changes over time and possible interaction between intervention and time, a series of mixed model analyses of covariance (ANCOVA) were conducted for the outcome variables, i.e. QoL, anxiety and depression. To take the variance at baseline into consideration, the baseline measurements of outcome variables were included as covariates.

Hierarchical regression analyses were made to investigate variables that explained the variance of outcome variables, namely QoL, anxiety and depression in the total sample. The order of the predictors was based on the basis of preceding correlation analysis and theoretical consideration (III). The variables that were imputed in the regression analysis for anxiety and depression were baseline measurement for anxiety and depression, the subscales of ISSI, SOC and the intervention programme. The variables that were included in the regression analysis for QoL were baseline measurement for QoL, SOC, age of family member, living together with the patient, subscales of ISSI and finally the intervention programme. Missing single items that were considered as missed by random, were imputed using Maximum Likelihood imputation (III) ^{121, 138}.

The power for paper II and III was calculated based on the Cantril Ladder of Life. To find a difference at a 5% significant level with a two-tailed test and 80% power for a clinically relevant difference with three points, a minimum of 76 individuals was needed.

In paper IV qualitative content analysis according to Patton ¹³⁶ was used to analyse the interviews. Qualitative analysis is used to analyse interviews about the responder's experiences, opinions, knowledge or feelings ¹³⁶.

The interviews were transcribed verbatim, and after transcription they were listened through simultaneously while reading the transcript. To get a wholeness of the content, the interviews were read through several times. Two of the authors coded the text-units independently, and the coding was discussed and modified. By coding independently important insight can be seen by two persons looking at the same data ¹³⁶. During the analytic process the codes were modified several times. The codes were sorted into eight subcategories and thereafter into three categories. Representative quotations are shown for each subcategory for credibility ¹³⁹.

ETHICAL CONSIDERATIONS

The studies in this thesis have been approved by The Karolinska Institutet Ethics Committee North.

A core principle of research ethics is the individual's possibility to freely give their informed consent. In paper I-IV an information letter, outlining the aim of the actual study including an assurance of confidentiality, voluntary participation and the right to withdraw from participation at any time, was sent to all presumptive participants.

In order to accomplish as complete a response frequency as possible in paper I, the first author telephoned the patients after one written reminder if there was still no response.

They were asked to participate in a telephone interview where the questionnaire was filled in by the interviewer. It could be seen as intrusive to telephone the patient but they had the opportunity to receive more information and/or decline participation. Of the 73 patients that were contacted by phone, 53 patients declined participation, and the most common reason given was no desire to participate.

In paper II and III, in cases where death of a patient occurred, the family members in the intervention group were invited to remain in the group or to choose to end participation. All family members of deceased patients chose to end their participation.

In paper IV, to optimize the interview situation the place and time for the interview was decided in agreement between the interviewer and the informants, with the intention to meet family members' wishes. To fulfil acceptable interview conditions sufficient time was given for each interview. Qualitative interviews may be considered as intrusive as informants share thoughts and experiences which they perhaps may not want to share¹³⁶. However, the interviews in general did not deal with highly personal matters. The informants were encouraged to speak freely and were not pressed to talk about matters they did not want to talk about. The informants were asked for permission to tape record the interview and were informed that it would be transcribed verbatim. They were also asked for permission to use quotations from the interviews.

To ensure confidentiality in paper I-III all questionnaires were provided with an identification number to protect the privacy of the participants¹⁴⁰. The participants in paper II-III signed an informed consent to acknowledge participation and to assure the participants' confidentiality in the IG, i.e. not to reveal the identity of other participants and not to reveal private aspects that may arise in the educational sessions. In paper IV the names of the participants were not written in the transcriptions. Name registers, tape recordings and transcriptions were stored so that no outsider could have access to information about the participants¹⁴⁰. The participants were informed that publishing of the results would not be at the individual level.

MAIN RESULTS

The overall aim of this thesis was to achieve an understanding of the effects of a group-based multi-professional educational programme for family members of patients with chronic heart failure and to investigate social network, social support and perceived loneliness in patients with chronic heart failure.

PERCEIVED LONELINESS AND SOCIAL SUPPORT IN PATIENTS (I)

Perceived loneliness

One hundred and forty-six patients answered the loneliness question, and of those responding, 29 (20%) reported perceived loneliness. Women reported loneliness to a higher extent than men ($p < 0.001$). The mean age of those reporting loneliness was lower than in the group that did not report loneliness (72 years ± 12.4 vs. 76 years ± 9.6 , $p = 0.024$). Those patients that were living together with someone/married reported less perceived loneliness. There were no differences related to occurrence of previous disease, duration of CHF or medical treatment between those who reported loneliness compared to those who did not.

A multivariate logistic regression analysis showed that a low ADSI (adequacy of social integration) score, female gender, younger age (< 65 years) and low score in AVSI (availability of social integration) were significant independent variables for perceived loneliness.

The patients who perceived loneliness had more hospitalisations episodes (3.1 ± 2.2 vs. 2.1 ± 1.6 , $p = 0.027$) and more number of days at hospital (17 ± 18.5 vs. 7.4 ± 7.0 , $p = 0.044$) during the year. Sixty seven patients of the total sample were readmitted at least once to hospital during one year, 14 patients of those 29 (48%) who reported loneliness and 53 patients in those 117 (45%) not reporting loneliness.

Social network and social support

There was no difference between men and women in either of the dimensions of social network and social support. Patients that were married/living together with someone reported higher in all subscales except ADSI, i.e. adequacy of social relationships. Younger patients (< 65 years) reported lower ADAT, i.e. lower satisfaction with close relationships although they did not report a lower number of close relationships than those ≥ 65 years. The patients that reported perceived loneliness scored lower in all subscales than those not reporting loneliness, i.e. they had a lower number of people available for support and were less satisfied with the number. They also had fewer close intimate relations and were less satisfied with them.

EFFECTS OF THE EDUCATIONAL PROGRAMME (II-IV)

Heart failure knowledge of family members (paper II)

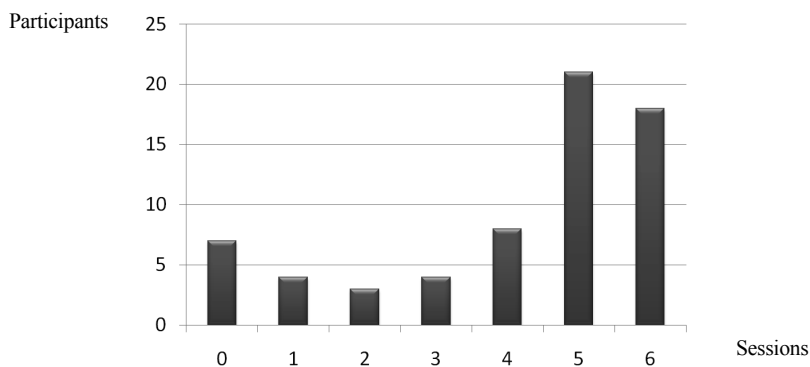
At baseline there was no difference between IG and CG in knowledge score (IG 13.5 ± 3.0 vs. CG 13.4 ± 2.8 , $p = 0.892$). Family members in both groups increased their knowledge between first measurement and second measurement, and the knowledge

remained between the second and third measurement. However, the family members in the IG had statistically significant higher score in knowledge at both second measurement (IG 16 ± 1.9 vs. CG 14.9 ± 2.1 , $p=0.006$) and third measurement (IG 16.5 ± 1.3 vs. CG 14.8 ± 1.8 , $p<0.001$) than family members in the CG.

Subgroup analysis was also conducted in the IG between participating 1-3 sessions or 4-6 sessions. There were no statistically significant differences between the groups in knowledge score. The most common reason for not attending at some of the sessions were: ending participation, not able to come for some sessions and own illness.

Attendance rate at the sessions in the IG are shown in figure 1.

Figure 1. Attendance rate of participants in the intervention group



Seven family members did not participate at any of the sessions. Eleven family members participated 1-3 sessions and 47 family members participated 4-6 sessions.

Healthcare utilization (paper II)

There were no statistically significant differences between the patients in IG or CG concerning hospitalisation, neither in frequency of readmission (IG 2.4 ± 1.8 vs. CG 2.0 ± 2.0 , $p=0.234$) nor number of days in hospital (IG 20.4 ± 16.7 vs. CG 14.6 ± 19.4 , $p=0.105$). In total 45 patients were readmitted at least once during 18 months due to CHF as first diagnosis; in the IG 17 (29%) and in the CG 28 (62%), ($p=0.085$). In the Kaplan-Meier analysis there was no statistically significant difference in first readmission to hospital between the two groups ($p=0.181$).

Additional results

In the total sample 84 patients were readmitted due to all causes at least once during 18 months; in the IG 40 (69%) and in the CG 47 (75%), ($p=0.491$). No differences between the groups in frequency of readmission to hospital were found nor number of days in hospital between the groups (table 4). In the Kaplan-Meier analysis there was no statistically significant difference in first readmission to hospital between the two groups ($p=0.82$).

Table 4. Numbers of readmissions to hospital due to all causes

Group	Mean (\pm SD)	Median (Range)	<i>p</i> -value IG vs. CG
IG n=40	2.6 (\pm 2.0)	2.0 (1-8)	0.388
CG n=47	2.9 (\pm 2.5)	1.0 (1-15)	

Numbers of days hospitalised due to all causes

Group	Mean (\pm SD)	Median (Range)	<i>p</i> -value IG vs. CG
IG n=40	18.8(\pm 21.4)	16.5 (0-93)	0.568
CG n=47	24.4 (\pm 31.6)	8.5 (0-139)	

Quality of life, anxiety and depression in family members (paper III)

At baseline there were no differences between the IG and the CG in QoL, anxiety and depression. The mixed Analysis of Covariance (ANCOVA) for QoL, anxiety and depression revealed no main effects in either intervention, i.e. due to the educational programme, or change over time between second and third measurement. Neither were there any interaction effects between the groups nor change over time. Descriptive data on anxiety, depression and QoL are shown in table 5.

Table 5. Descriptive data on anxiety, depression and quality of life

	First assessment		Second assessment		Third assessment	
	IG n=65	CG n=63	IG n=56	CG n=54	IG n=55	CG n=51
Anxiety	6.2 (\pm 3.9)	5.9 (\pm 3.6)	5.6 (\pm 3.9)	5.1 (\pm 4.0)	4.6 (\pm 3.9)	5.4 (\pm 4.0)
Depression	3.8 (\pm 3.0)	3.6 (\pm 2.7)	3.7 (\pm 3.5)	3.6 (\pm 2.3)	3.5 (\pm 3.1)	4.3 (\pm 3.6)
QoL	6.9 (\pm 1.7)	7.3 (\pm 1.6)	6.8 (\pm 2.0)	7.1 (\pm 1.9)	7.1 (\pm 1.9)	6.9 (\pm 2.0)
SWED-QUAL						
Role limitations, emotional	77 (\pm 27.0)	77 (\pm 26.8)	71 (\pm 29.3)	76 (\pm 28.6)	80 (\pm 22.9)	76 (\pm 31.4)
Emotional wellbeing	75 (\pm 20.9)	78 (\pm 18.4)	76 (\pm 21.1)	79 (\pm 18.1)	80 (\pm 18.5)	78 (\pm 20.9)
Quality of sleep	73 (\pm 23.1)	74 (\pm 21.8)	71 (\pm 18.3)	75 (\pm 22.3)	75 (\pm 19.8)	75 (\pm 21.2)
General health perception	83 (\pm 16.3)	83 (\pm 14.5)	83 (\pm 18.4)	82 (\pm 16.4)	83 (\pm 16.7)	81 (\pm 18.8)
Satisfaction with family life	89 (\pm 14.7)	86 (\pm 18.3)	85 (\pm 18.6)	86 (\pm 16.8)	88 (\pm 15.4)	89 (\pm 14.3)
Relationship with partner	83 (\pm 18.1)	81 (\pm 16.3)	83 (\pm 19.3)	83 (\pm 17.7)	83 (\pm 18.5)	83 (\pm 16.3)

Mean (\pm SD), QoL=quality of life, IG=Intervention group, CG=Control group

In the hierarchical regression analysis baseline measurement of anxiety and depression and ADSI were the independent variables that significantly predicted both anxiety and depression at third measurement, accounting for 35% of the variance for anxiety, and 37% for depression. In the regression analysis of QoL, baseline measurement of QoL and age of family members were the predictors at the third measurement of QoL accounting for 25% of the variance.

Experiences of participating in the educational programme (paper IV)

Three categories were developed through the analysis: “making the disease comprehensible”, “increasing involvement” and influencing family members’ wellness.

Making the disease comprehensible

Family members increased their knowledge and attained an overall view of CHF. Through the increased knowledge they gained a better understanding and tolerance for the ill person with CHF and his/her condition. Signs and symptoms were intertwined with other aspects related to aging and/or other diseases. Family members expressed that their increased knowledge sometimes made it difficult to distinguish if it was symptoms related to CHF or symptoms caused by natural aging process or other circumstances related to other diseases. Most of the information discussed in the programme was not troublesome to hear but for some family members the increased knowledge created some worries, and the most burdensome was to realise the seriousness of the disease.

Creating involvement

Family members described that they felt more knowledgeable and shared their knowledge with the ill person. They became someone the ill person could turn to and discuss different issues with and they were more actively involved in the ill person’s self-care. Family members had realised the importance of being observant of symptoms, such as oedema of the legs and to remind the ill person to be observant about their weight and not drink too much fluid. They said that their expanding consciousness about the importance of self-care motivated them to support the ill person to take walks.

Influencing family members’ wellness

To meet others in the same situation was expressed as positive by family members, and it created a feeling of being someone and of being seen. To discuss difficulties and worries with others was expressed as a relief and they realised that they were not alone in their situation. By sharing experiences they understood how others felt and that it was acceptable to feel the way they did sometimes, without guilt for their feelings and reactions. Some of the family members’ had gained insight as to the importance of taking care of their own health.

Self-reported evaluation of the educational programme

Results from the self-reported evaluation showed that most family members reported great satisfaction with the structure and content of the programme but a majority would have preferred to have shared the education and meetings together with the ill person or as a complement to this educational programme.

DISCUSSION

MAIN DISCUSSION

In this thesis different outcomes have been evaluated in a multi-professional educational programme for family members of patients with chronic heart failure. Social network as well as social support and perceived loneliness were also investigated in patients with CHF. The patients perceiving loneliness had more days in hospital and higher frequency of re-admission for different causes and they also reported lower social network size and social support. Further the findings showed that disease specific knowledge increased among family members that participated in the educational programme as well as in family members that were included in the control group. The acquired knowledge was subjectively expressed by family members who had participated five to six sessions, as meaningful and useful in daily life for both the family member and the patient. Due to the increased knowledge, family members became more understanding of the patient's situation, increased their involvement in the patient's self-care management and also learned how to monitor symptoms. One assumption with the programme was that if family members increased their disease-related knowledge this might have had the possibility to influence the patients' self-care management and thereby reduce health care utilization of the patients. However, there were no significant differences in health care utilization for the patients in the intervention group and the control group. The educational programme did not show any effects on family members' anxiety, depression and/or quality of life, but some information led to worries for some of the family members and new questions arose. The most burdensome, expressed by family members, was to learn that chronic heart failure is a lifelong and serious disease. Family members that had participated in the educational programme were overall satisfied with the content and the design of the programme.

Perceived loneliness, social network and social support

In paper I the findings showed that patients that were married/living together with someone reported greater social network and support but were not more satisfied with the number of social relationships than those living alone. Patients under 65 years of age reported lower satisfaction with close relationships although they did not have fewer intimate relationships. In a study by Bennet et al.¹⁴¹ it was found that men under 65 years age scored lower social support than men 65 years or over and women less than 65 years of age, but at the same level as women 65 and over. In our study we did not see any gender differences. Those perceiving loneliness scored lower in all dimensions of the social support instrument.

About 20 percent of the patients perceived loneliness, which is in line with what other studies have shown^{117-118, 142}, i.e. the majority do not perceive loneliness. Women reported loneliness to a higher extent than men, which is in line with other studies^{117, 143-145}. It might be that women are more prone to report a feeling of loneliness than men as Peplau et al. suggested (in Andersson¹⁴⁶). In contrast in a study by Lauder et al.¹⁴⁷

men reported more loneliness than women. Those reporting loneliness were younger, which also has been reported in other studies^{144, 147}. One study showed that people under 50 years of age reported loneliness to a higher extent than those over 50 years¹⁴⁷. On the other hand in a study by Jylha et al.¹¹⁹ it was found that loneliness increased with age. To be diagnosed with CHF in middle-age might affect daily life more than receiving the diagnosis at an older age. Younger persons that are still working and are used to a more active and social life may not have the energy to continue with their lives as before. Their professional life, life plans in general and the social life might be limited¹⁰. Since the symptoms of CHF are diffuse and are sometimes intertwining with normal aging, persons who are diagnosed with the disease in older age may not be affected as much as those diagnosed in the middle age.

Loneliness can be both social and emotional loneliness⁸⁴. In paper I perceived loneliness was measured by one single-item question and therefore *loneliness* is not separated into social and emotional loneliness. By using a single-item question loneliness was measured as the person understands it¹¹⁹. Experiencing loneliness is not necessarily the same as being alone⁸³. We found that some patients who reported loneliness also reported a high number of social contacts. The group that reported a feeling of loneliness scored, as mean value, significantly lower in all dimensions of the social support measurement, i.e. they reported fewer contacts both for social support and emotional contacts and they were less satisfied with both. Holmen et al.¹¹⁸ found that satisfaction with social contacts and to have good friends to talk with are both closely related to not feeling lonely. It could be postulated that having family members or friends that have a greater knowledge about your condition might ease the feeling of loneliness. Having social support is of importance for patients with CHF, and it has been shown that increased knowledge in the spouse gives a better understanding for the individual with heart failure²¹.

Those patients reporting feeling of loneliness had more health care utilization due to all causes than those not feeling lonely. This is in line with findings by Geller et al.¹⁴⁸, who found that people who scored high on feeling of loneliness visited the emergency department more often, it has also been found that social isolation increases hospitalisation¹⁴⁹. Although those feeling lonely in our study did not have more severe CHF, they could still have been affected by other factors in their lives. In a study by Cappatio et al.¹⁵⁰ it was shown that persons feeling lonely had poorer sleep than those not feeling lonely, and in a study by Lauder¹⁵¹ the persons that felt lonely were more prone to smoke and to be overweight. Loneliness has also been found to be associated with depression^{142, 152}. It might be considered that not having anyone to talk to about worries and worsening of health could result in seeking more hospitalization.

Educational programme

The findings showed that disease-related knowledge increased in both the intervention group (IG) and the control group (CG), which is in line with findings from evaluations of educational programmes directed at patients with CHF¹⁵⁻¹⁶ and for family members of patients with CHF or stroke^{22, 110}. Family members who had participated in the IG

had significantly higher knowledge at second and third measurement compared to family members in the CG which also has been found in a study by Franzen-Dahlin et al.¹¹⁰. In one of the earlier reported evaluations of an educational programme for family members with a shorter intervention period, the knowledge level declined at 3 months²². The current study found no differences in disease specific knowledge between those participating one to three sessions and those participating five to six sessions in the IG. The clinical relevance in the small but significant difference in knowledge between family members in IG and CG might be questioned. The act of filling in a questionnaire about CHF could be enough to obtain knowledge, which was possibly the case for family members in CG. An explanation for the increased knowledge in the control group could be that family members who accepted participation were highly motivated to learn about CHF. The questions in the questionnaire could have given a direction to what is needed to know and family members in the CG might have been stimulated to seek the information about CHF that they needed on their own.

Knowledge in itself does not always change behaviour, but it can contribute to important effects⁹⁶. The acquired knowledge was useful in daily life both for family members and for the patients, in that the family members became more tolerant and understanding of the patients in different situations, both in medical and psychological aspects. Also Duhamel et al.²¹ found that both spouses and the patient learned how to deal with the disease and spouses expressed a better understanding of the patient with CHF. Further, family members in our study expressed that they became more aware of the symptoms and more involved in treatment and self-care of the patients. They also became someone the patient could have discussions with about disease-related issues, and further they became a resource for the whole family since they knew more about the disease. According to adult learning theory¹⁰³ the learners, in our case family members, need to know why they are learning something. Adults become ready to learn those things they need to know and to be able to do in order to effectively deal with their situation. They are motivated to learn something when they perceive that it will help them to perform tasks or deal with problems that they are confronted with in their life situation. This was a motivated group who wanted to learn about CHF to be more capable of handling different situations, and they increased their disease-specific knowledge and could use the knowledge in daily life.

An assumption with the educational programme was that increased knowledge among family members would decrease patients' needs of health care utilization. However, frequency of readmission and number of days hospitalized did not differ between the groups. We have not found any other studies that have evaluated health care utilization as an outcome of a family member educational programme. Previous research has found that social support may decrease patient health care utilization^{78, 80, 86}, further some studies of patient education have been shown to reduce health care utilization^{18, 105}. A reason for no significant difference might be lack of statistical power or that family members actually were more observant about worsening of the CHF and therefore sent the patient to hospital at an earlier stage. The family members in the CG

also increased their disease-related knowledge, and we do not know if or how they applied the increased disease-related knowledge in daily life.

Another underlying assumption of the educational programme was that improved knowledge would have an effect on family members' level of anxiety and depression since studies have shown that lack of knowledge might result in anxiety⁹⁵ and worries⁴. Despite the improvements in disease specific knowledge the study did not show any effect on level of anxiety and depression measured with standardised questionnaires. However, the findings in paper III showed that the family members that participated in the study did not have a high level of anxiety or depression at start of the study; the level of the family members' anxiety and depression were in line with a general adult population¹²⁵. Other studies have shown that family members of patients with CHF have a high level of anxiety and depression^{67, 94}. Our results might be explained by the fact that 41 percent of the family members did not live together with the patient. The QoL of the family members was not affected by the educational programme. Neither, did they score low in QoL, although some studies have shown that family members of patients with CHF have low QoL^{61-63, 93}. Younger family members in paper III had better QoL, which also can be explained by that they were more often not living together with the patient. Nauser et al.¹⁵³ have recently developed a caregiver-specific instrument to measure impact of care giving on QoL in family members of patients with CHF, which can be good to apply in the future.

To increase our understanding of the experiences of being offered an educational programme an interview study was performed with some of the family members that had participated five to six times, one year after completion of the programme. Family members expressed with their own words that their disease-specific knowledge increased and some of the family members expressed that some of the knowledge created worries. The main reason was the insight into the seriousness of CHF and that the disease was life-long and thereby created insecurity of the future. But, they still said it was better to get proper information and some of the family members expressed that they already had worries about the ill person prior to the educational programme. To not receive information has in earlier studies been shown to create worry³⁻⁴. In a qualitative study by Imes et al.² the majority of the family members of patients with CHF expressed that they missed prognostic information from caregivers and felt that it would have been helpful to prepare for the future. However, most of the family members that received prognostic information in that study did not find it particularly helpful, while some of those receiving information about prognosis found it to provide hope and was useful in planning for the future. By increasing knowledge also new questions were raised. It could be quite difficult to separate worsening of CHF from illness caused by other circumstances that affected the patient's physical condition. Further, family members sometimes had difficulties to separate symptoms of CHF from symptoms of the normal aging process. In a study by Ekman et al.⁵⁵ older patients with CHF perceived some of the symptoms such as tiredness, fatigue and breathlessness as a natural part of oneself and life.

Although we did not find any significant differences in paper III, in paper IV we found through subjective experience from family members that they felt more knowledgeable, self-confident and more secure after attending the educational programme. This might have to do with that human beings' experiences are complex and are not always possible to capture in standardised questionnaires but can be detected in interviews where family members are invited to freely reflect on their experiences in their own words. Qualitative methods produce detailed information about thoughts and experiences in a small number of people. This increases the depth of understanding of the people studied ¹³⁶.

The design of the educational programme was overall considered as good by the participants. To meet other family members in the same situation and share thoughts and experiences was seen as very helpful and a relief. Other studies in patients with coronary disease have shown that getting together in a group with others in the same situation was helpful ^{114, 154}. Group sessions provided an opportunity to share experiences, receive practical and emotional support from each other and an opportunity to talk about important things such as the meaning of life ^{114, 154}. A majority of the family members had wished to attend the programme together with the patient, but on the other hand some family members expressed that they would not have been able to speak freely if the patient would have been present. It might have been advisable to have invited the patients to some of the sessions so they could share experiences with the group. In Clark et al. ¹¹³ both family members and patients participated in the family partner intervention. First together and thereafter divided into two groups; family members in one and patients in another where they could discuss their own issues. Even though family members did appreciate the opportunity to share experiences in the group, some missed an opportunity to talk in private about their own special situation, as was found in another study in family members of stroke patients ¹¹⁰.

It might be questioned if it is realistic to implement the educational programme when the only significant results were increased disease-specific knowledge and the family members' (those that participated in five to six sessions) subjective experience of being more knowledgeable, self-confident and more involved in the self-care.

The educational programme offered to the family members had a health care perspective in that the content was adopted from ESC Guidelines. According to the adult learning theory ¹⁰³ it is important to take into consideration family members' experiences, what family members need to know and what they feel that they perceive will help them to deal with problems they are confronted with. Even though we found that family members learned about CHF and used the knowledge, we do not know how many sessions the programme should optimally include. Family members expressed that they were satisfied with the content. On reflection, however, perhaps a change in perspective could be the right way forward for planning future education programmes. By starting with the perspective of the family member, assessing what they perceive their needs of knowledge to be may make the programme even more applicable to meet knowledge needs.

METHODOLOGICAL CONSIDERATIONS

The inclusion of patients in paper I was retrospective, i.e. all the patients were recruited after a 4-month period. This could make the findings more unreliable than if a prospective design was used. A prospective design could have allowed for inclusion of more participants as we would have consecutive data and thereby would have included participants that had died between the hospitalization period and screening time. The patients' health care utilization was followed for 12 months, prospectively from the last hospitalisation during the 4-month period. The health care utilization was collected from a register from one university hospital. Therefore we do not know if the patients had been hospitalised at other hospitals, and neither do we have information about how often the patients sought care at the district health care centre.

The use of two different methods, i.e. a self-reported questionnaire and a telephone interview, for collecting data in paper I could be questioned. Perhaps the answer will not be the same if the questionnaire was filled-out by the respondent or during an oral telephone interview with a researcher. This was done to achieve as high a response rate as possible, which reached 70% in this study, a level which is recommended in the literature ¹²¹.

By measuring feeling of loneliness with one single-item question the feeling of loneliness will be measured as understood by the person answering, as a genuine subjective experience ¹¹⁹. The single-item question is the easiest way of measuring loneliness, but the simplicity of the one single-item question is also a limitation since it does not separate emotional and social loneliness ¹⁵⁵. If the aim had been to identify the type of loneliness it would have been more appropriate to measure the feeling of loneliness with a scale including items reflecting social and emotional loneliness.

The family members in paper II and III that accepted participation were motivated to learn more about CHF and are therefore a selective sample. On the other hand if an educational programme for family members would be provided in regular health care, probably it would be motivated family members who are willing to participate in such programme. Therefore the sample could possibly be seen as representative for those family members who are willing to participate in an educational programme. Some of the dropouts in the IG could be explained by the long time needed for recruiting participants (mean time 4 months). This might have been prevented by another inclusion process, as for example by recruiting the patients while they were still hospitalised. Just by filling-out forms about disease specific knowledge gives a direction about what is of importance to know, and therefore the knowledge increased even for family members in the CG, i.e., those who did not participate in the education programme. The questionnaires at second and third measurement were sent home to the participants and therefore we have no control over who actually filled in the questionnaires. This was, however, done in both groups.

The implementation of the educational programme was time consuming, i.e., it took a long time to gather the family members using our strict inclusion criteria. The mean time for gathering a group was 4 months, and with less restrictive inclusion criteria the time for gathering a group could have been less.

In study IV family members had the opportunity to verbally tell about how they experienced the education programme in their own words, and thereby evaluated the importance of the programme in another way than by means of a questionnaire. Eleven family members participated which can be seen as a rather small sample size. There are no precise rules for sample size in qualitative designs¹³⁶, and the informants selected were seen as fulfilling this study's needs. The inclusion criterion for family members in paper IV was that they had participated in five to six sessions of the possible six sessions. Results of the interviews might have been different if family members that had participated in fewer sessions had been included in the study.

The informants were all familiar with the interviewer after attending the educational sessions where the interviewer was present. This might have influenced the results, in that the participants were perhaps less prone to criticise the programme. However, the interviewer did ask if there was any information that they could have done without or felt was missing. The family members were also asked if they felt there was something in the programme could have been different. By knowing the interviewer the participants could feel comfortable by seeing someone they knew and therefore feel free to express their thoughts. The credibility deals with how well the categories represent the data. One approach for this is to use quotations to illustrate the family members' experiences¹³⁹. Secondly it is of value to have several persons analysing the data for credibility^{136, 139}. In the work with the analysis of the interviews in paper IV, two of the authors read several interviews independently and discussed coding leading to consensus which increases the credibility of the analysis.

CONCLUSION

- Twenty percent of patients with chronic heart failure perceived loneliness which was associated with increased health care utilization and with lower social network and social support. The group that perceived loneliness was younger and more often women.
- The educational programme increased disease-specific knowledge among family members of patients with chronic heart failure. However, health care utilization for the patients did not differ between the groups.
- The educational programme did not have an effect on quality of life, anxiety and depression in family members of patients with chronic heart failure. However, important variables such as adequacy of social support influenced anxiety and depression, and the age of the family members influenced their quality of life.
- Family members experienced the educational programme as overall positive, with increased self-confidence to support the patient and by feeling more involved in the disease process of the patient and in their self-care management.
- Overall conclusion: The implemented group-based multi-professional educational programme for family members of patients with chronic heart failure seemed to have a subjectively experienced positive effect. The family members gained increased knowledge, confidence and understanding of the disease, which made it easier for them to support the patient in their self-care management. However, this educational programme did not have an effect on the evaluated variables, i.e. levels of quality of life, anxiety and depression. Perceived loneliness in patients with chronic heart failure was most common in women and younger patients, and this was associated with health care utilization, social network and social support.

CLINICAL IMPLICATIONS AND FUTURE RESEARCH

Clinical implication

- Early identification of patient perceiving loneliness might be needed in that the feeling of loneliness is an indicator for re-hospitalisation. It could be easily done with one single question to the patient.
- It is important that family members are seen as a resource for the patients and that they receive knowledge to be able to provide support for the patients. The family members became more knowledgeable and received self-confidence by our educational programme. However, alternative methods should be considered for the design of educational programmes in the future.

Future research

As perceived loneliness in patient was a risk indicator for re-hospitalisation, it would be of interest to investigate how to avoid re-hospitalisations in patients that are feeling lonely. Areas to investigate could include: establishing contacts with nurses in face-to-face sessions, or by telephone contact, or establishing contacts with other health care professions.

One question is how an educational programme for family members of patients with heart failure should be optimally designed. Most of the family members wanted both to be together with the patient and also with other family members in the same situation in an educational programme. One way to find out what family members want and need in an educational programme is by performing interviews to aid in the design of an effective educational programme in the future.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Hjärtsvikt medför stora inskränkningar i livet både för personen som har hjärtsvikt och deras närstående, både emotionellt, socialt och psykiskt. I Sverige beräknas det att ca 200 000 personer har hjärtsvikt, och förekomsten ökar med ålder. Symtomen på hjärtsvikt är ofta diffusa och vanligast symtom är andfäddhet och trötthet. Tidigare forskning har visat att brist på socialt stöd till patienter med hjärtsvikt kan leda till återinläggning. Då en person blir diagnostiserad med en kronisk sjukdom uppkommer ett behov av att få information och kunskap, både för den sjuke och närstående. Det finns utbildningsprogram som har utvärderats där närstående och patienten med hjärtsvikt fått utbildning tillsammans. Men det finns få studier om utbildningsprogram som vänder sig endast till närstående till patienter med hjärtsvikt.

Det övergripande syftet i avhandlingen var att undersöka förekomst av socialt stöd och känsla av ensamhet hos patienter med hjärtsvikt, samt att utvärdera effekten av ett multiprofessionellt utbildningsprogram för närstående till patienter med hjärtsvikt.

Syftet med **delarbete I** var att undersöka upplevd ensamhet och socialt stöd hos patienter med hjärtsvikt, och att undersöka om ensamhet och socialt stöd var associerat med kön, ålder, slutenvårdskonsumtion och mortalitet. Etthundrafyrtionio patienter med hjärtsvikt deltog i studien, 71 kvinnor och 78 män och medelålder i gruppen var 76 år. Resultatet visade att 29 (20%) av deltagarna upplevde känsla av ensamhet. De var fler kvinnor och den gruppen hade en lägre medelålder. Deltagarna som upplevde ensamhet uppgav mindre socialt nätverk, både i det större nätverket och nära kontakter och de var också mindre nöjda med det sociala nätverket. Av de patienter som hade återinläggningar, så hade de som upplevde ensamhet fler återinläggningar och fler dagar på sjukhus, jämfört med de som inte upplevde ensamhet.

Delarbete II och III utgår från samma studie, där vi utvärderar effekten av ett multiprofessionellt utbildningsprogram om hjärtsvikt för närstående. Närstående lottades till att delta utbildningsprogram eller till en kontroll grupp som fick information enligt avdelningens rutiner. De som lottades till utbildningsprogrammet träffades vid sex tillfällen under sex månader i en grupp på åtta patienter. Programmet innehöll olika och gavs av ett multiprofessionellt team. De olika teman var: medicinska aspekter (läkare), egenvård (sjuksköterska), nutrition vid hjärtsvikt (dietist), träning vid hjärtsvikt (sjukgymnast) samt psykosociala aspekter (kurator). Deltagarna fyllde i frågeformulär vid tre tillfällen under ett år.

I **delarbete II** var syftet att undersöka om närstående till patienter med hjärtsvikt ökade sin kunskap om hjärtsvikt genom att delta i utbildningsprogrammet. Vidare undersöktes även om slutenvårdskonsumtionen minskade för patienten med hjärtsvikt. Resultaten visade att närstående ökade sin kunskap, både de som deltagit i utbildningsprogrammet och de som lottats till kontroll gruppen, men närstående som

deltagit i utbildningsprogrammet ökade mer i kunskap. Vi fann inga skillnader i slutenvårdskonsumtion för patienterna med hjärtsvikt under en period på 18 månader. I **delarbete III** var det primära syftet att undersöka om närståendes livskvalitet, ångest och depression påverkades av deltagande i utbildningsprogrammet. Det sekundära syftet var att undersöka faktorer som påverkade förändringar i livskvalitet, ångest och depression under tiden för studien i hela gruppen.

Resultatet visade att interventionen inte påverkade livskvalitet, ångest och depression mellan grupperna, över tid eller inom grupperna. Vi fann att yngre närstående skattade bättre livskvalitet. Det fanns vissa individuella förändringar i livskvalitet, ångest och depression över tid och det som påverkade förändring av ångest var närståendes grad av ångest vid studiestart och tillfredsställelsen med socialt stöd. Förändring av depression påverkades närståendes grad av depression vid studiestart och tillfredsställelse av socialt stöd. De faktorer som påverkade förändring i närståendes livskvalitet var närståendes ålder samt deras livskvalitet vid studiestart.

Syftet med **delarbete IV** var att beskriva hur närstående till patienter med hjärtsvikt upplevde att delta i det gruppbaseade multiprofessionellt utbildningsprogrammet. Datainsamling skedde genom intervjuer och en skriftlig utvärdering. Elva närstående som deltagit minst fem till sex gånger, intervjuades och 53 närstående besvarade den skriftliga utvärderingen. I analyserna av intervjuerna framkom tre kategorier: ”göra sjukdomen förstålig”, ”ökat engagemang” och ”påverkan på närståendes välbefinnande”. I kategorin ”göra sjukdomen förstålig” uttryckte närstående att de hade fått en ökad kunskap om hjärtsvikt och en ökad helhetsbild av hjärtsvikt och därigenom en ökad förståelse för den sjuke. Med ökad kunskap uppstod frågor som t ex: om symtomen var orsakat av försämring i hjärtsvikten eller berodde på naturligt åldrande. I kategorin ”ökat engagemang” framkom det att närstående kände sig säkrare i sin kunskap och hade blivit någon den sjuke kunde prata med angående sin hjärtsvikt och uppgav att de var mer involverade i patientens egenvård. Kategorin ”påverkan på närståendes välbefinnande” handlar om att det var värdefullt att träffa andra i samma situation och vikten av att ta hand om sig själv. I den skriftliga utvärderingen framkom att de flesta närstående var nöjda med utbildningsprogrammets såväl innehåll som upplägg. Majoriteten av deltagarna hade önskat att utbildningen genomförts tillsammans med patienten med hjärtsvikt, men det fanns de som uppgav att de inte hade kunnat tala lika fritt om den sjuke hade varit med.

Sammanfattning

Ensamhet är en viktig aspekt att ta hänsyn till då patienter med hjärtsvikt som upplever ensamhet har fler återinläggningar och fler dagar på sjukhus. Det gruppbaseade multiprofessionella utbildningsprogrammet för närstående till patienter med hjärtsvikt ökade kunskap hos närstående och tycktes ha en subjektivt upplevd positiv effekt. Närstående uttryckte att de fått ökad kunskap, ökad säkerhet angående hjärtsvikt och förståelse för sjukdomen, vilket gjorde det lättare för dem att stödja egenvården hos personen med hjärtsvikt. Däremot, gav utbildningsprogrammet ingen effekt på livskvalitet, ångest och depression hos närstående och inte heller på sjukhusvård för personen med hjärtsvikt.

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APPENDIX

Structure of the programme

- Was the number of sessions sufficient?
- Did the session start at a good time, i.e. 5 pm?
- Was each session long enough, ie 2 hours?
- Was the day at the week good?
- Was the number of participants appropriate?
- Was the information before the sessions sufficient?

Content of the programme

- How did you find the education at the first meeting, medical aspects with the cardiologist?
- How did you find the education at the second meeting, self-care with the specialist nurse?
- How did you find the education at the third meeting, nutrition with the dietitian?
- How did you find the education at the fourth meeting, physical activities with the physiotherapist?
- How did you find the education at the fifth meeting, psychological aspects with the social worker?
- How did you experience the education overall?

Participants' view about attending the programme in a group with or without the ill person present

- How was it to attend this education together with other family members?
- Do you feel that you had the possibility to make yourself heard?
- Would you prefer to attend education together with the ill person?
- Would you want your sick relative to participate in this education programme with you?

Expectations of the programme

- Did the education correspond to your expectations?
- Did you feel anything was missing?
- Did you wish anything more from the education?

Usefulness

- Have you applied anything you learned?
- Have you discussed your new knowledge to the person with CHF?