MARIE HOLST

SELF-CARE BEHAVIOUR AND DAILY LIFE EXPERIENCES IN PATIENTS WITH CHRONIC HEART FAILURE

isbn/issn 978-91-7104-215-6/ 1653-5383

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SELF-CARE BEHAVIOUR AND DAILY LIFE EXPERIENCES IN PATIENTS WITH CHRONIC HEART FAILURE
To me
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ABSTRACT

Chronic heart failure (CHF) is a progressive, complex, clinical syndrome resulting from structural and/or functional cardiac disorders that impair systolic and/or diastolic ventricular function. The dominating clinical symptoms are shortness of breath, fatigue, exercise intolerance and peripheral oedema. This considerably affects physical, psychological and social functions of the individual, often making normal daily life activity difficult. The treatment for CHF is both pharmacological and non-pharmacological. Patient education, support and counselling are important parts of the non-pharmacological treatment and aims among other things to improve self-care behaviour and adherence to the treatment.

Thirst is, in clinical practise, a common reason for complaint in patients with CHF. One factor that can cause or aggravate thirst is the recommendation to be restrictive with fluid intake. In international guidelines for CHF treatment, a fluid restriction of 1,5-2L/day is often recommended. However, neither is this recommendation based on scientific evidence, nor has it been investigated if and how such a recommendation affects the patients’ physical and mental health. The overall aim of this thesis was to describe and evaluate self-care behaviour and to describe daily life experiences in patients with CHF, with special reference to fluid intake.

The aims of Study I were to: (1) describe self-care with special regard to daily self-weighing and salt and fluid restriction in patients with heart failure in primary health care, during one year of monthly telephone follow-up after a single session education, (2) to describe gender differences in regard to self-care and (3) to investigate if self-care was associated with health-related quality of life. The study was a subgroup analysis of the interventional group from a larger randomised trial. No changes were found in self-care behaviour throughout the study period. The intervention had no effect on quality of life and no associations were found between quality of life and self-care behaviour. There were no statistically significant differences between the genders.
Study II was a randomised, cross-over trial with the aim to compare the effects of a restrictive to those of a liberal fluid prescription, on quality of life, physical capacity, thirst and hospital admissions, in patients who had improved from NYHA class (III-IV) CHF to a stable condition, without clinical signs of significant fluid overload. There were no significant differences in end-of-intervention between the two fluid prescriptions in quality of life, physical capacity or hospital admission. In sense of thirst and difficulties to adhere to the fluid prescription there were significant between-intervention differences in end-of-intervention in favour of the liberal prescription.

Study III was a secondary analysis of the data from study II with the aim to describe the self-reported fluid intake and its effects on body weight, signs and symptoms of CHF, quality of life, physical capacity and thirst in patients with stabilised CHF. The efficacy variables were analysed in relation to the median fluid intake of 19ml/kg bodyweight/day. Patients with an above median fluid intake experienced significantly less thirst and difficulties to adhere to the fluid prescription.

Study IV was an interview study with the aim to describe how persons with CHF experience and manage daily life. The interviews were analysed with manifest and latent content analysis. The experience of living with CHF is illuminated by the themes Hindering and Facilitating Forces. The distribution between these themes was equal which can be interpreted as despite the difficulties patients with CHF have, they are capable to create a good life for themselves.

The results of this thesis confirm the results from other studies regarding self-care behaviour and the experiences of living with CHF. It is the first study showing that it seems beneficial and safe to recommend a liberal fluid prescription, based on body weight, in stabilised patients with CHF. A liberal fluid intake has favourable effects on thirst and difficulties to adhere to the fluid prescription without any detectable effects on quality of life, physical capacity or morbidity. A larger self-reported fluid intake was not associated with any measurable negative effects on signs and symptoms of CHF, diuretic use, or physical capacity. Thus, a more liberal fluid intake may be advisable in patients with CHF who have been stabilised from an initial unstable clinical state.

II. Liberal versus restricted fluid prescription in stabilised patients with chronic heart failure: Result of a randomised cross-over study of the effects on health-related quality of life, physical capacity, thirst and morbidity. Marie Holst, Anna Strömberg, Maud Lindholm, Ronnie Willenheimer. *Submitted*


IV. The experiences of living with chronic heart failure. Marie Holst, Anna Strömberg, Ronnie Willenheimer, Maud Lindholm. *Submitted*

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## ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>CHF</td>
<td>Chronic heart failure</td>
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<tr>
<td>NYHA</td>
<td>New York Heart Association</td>
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<td>EHFScBS</td>
<td>The European Heart failure Self-care Behaviour Scale</td>
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<tr>
<td>EQ-5D</td>
<td>EuroQol</td>
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<tr>
<td>MLWHF</td>
<td>Minnesota Living with Heart Failure Questionnaire</td>
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<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
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<tr>
<td>HRQoL</td>
<td>Health-related quality of life</td>
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INTRODUCTION

Chronic heart failure (CHF) is a progressive, complex, clinical syndrome resulting from structural and/or functional cardiac disorders that impair systolic and/or diastolic ventricular function. The debut of CHF can be acute with severe signs and symptoms, such as pulmonary rales and shortness of breath, but often the symptoms develop gradually with various degrees of, for example, fatigue, dyspnoea and peripheral oedema. Naturally, this affects the individual’s health both physically and mentally. Lack of energy and fatigue are often described as limiting and this affects the life situation in many different ways. The prognosis of CHF is generally poor, approximately 60% of the patients die within five years after diagnosis. The goals of treatment are prevention, delaying disease progression, improving quality of life and prolonging survival. The treatment for CHF is both pharmacological and non-pharmacological and it is complex. In order to successfully adhere to the treatment and to perform self-care the patients need knowledge and skills. Different kinds of CHF programmes, with a variety of educational intensity have been developed, with the goal to improve self-care and adherence to treatment and, thereby, to improve quality of life and reduce morbidity and mortality.

Nurses involved in the care of patients with CHF often meet patients that complain about thirst. The reasons for thirst can be several: (1) increased activation of the neurohormonal systems stimulates the thirst centre in the hypothalamus, (2) xerostomia induced by diuretic therapy intensifies sense of thirst and (3) and recommendation restrict fluid intake can increase the perceived thirst. Many patients with CHF are advised restrict fluid intake because of the risk of fluid overload. The recommendations given in guidelines are 1.5-2L/day, but this recommendation has no support in the scientific literature. Formerly, when the pharmacological treatment not was as effective as today fluid restriction was a natural prescription.
In my ten years as a nurse working at a ward specialising in the care of patients with CHF, thirst, has often been brought up by the patients as an important problem. Several questions arose: What scientific evidence is the 1.5L/day prescription based on? Is it reasonable for a person weighing 50 kg to have the same fluid intake prescription as a person weighing 80 kg? Is it possible to individualise the fluid prescription? The essence of this thesis originated from these simple and common sense questions. The overall aim was to describe and evaluate self-care behaviour and to describe daily life experiences in patients with CHF, with special reference to thirst and fluid intake.
BACKGROUND

CHF is a complex syndrome and it is therefore difficult to find a definition that covers all features\textsuperscript{15}. The failing heart is unable to pump blood at a rate commensurate with the requirements of the metabolizing tissues or can do so only at the expense of an elevated filling pressure\textsuperscript{16}. Haemodynamic, neurohormonal and cellular compensatory mechanisms delay symptom debut and reduce symptoms, but the capacity of these mechanisms to sustain cardiac performance is limited and CHF develops. Typical signs and symptoms of CHF are breathlessness and/or fatigue, at rest or during physical activity, and peripheral oedema. The diagnosis should be based on symptoms of CHF and, objective evidence of cardiac dysfunction, and in case of uncertainty a typical response to treatment directed towards CHF may give the diagnosis\textsuperscript{14}. The severity of CHF is often estimated by the New York Association Classification (NYHA)\textsuperscript{17} (Table 1).

\begin{table}
\centering
\begin{tabular}{|l|p{14cm}|}
\hline
NYHA Class I & No limitation: ordinary physical exercise does not cause undue fatigue, dyspnoea or palpitations. \\
\hline
NYHA Class II & Slight limitation of physical activity: comfortable at rest but ordinary activities result in fatigue, dyspnoea or palpitations. \\
\hline
NYHA Class III & Marked limitation of physical activity: comfortable at rest but less than ordinary activity results symptoms. \\
\hline
NYHA Class IV & Unable to carry out any physical activity without discomfort: symptoms of CHF are present even at rest with increased discomfort with any physical activity. \\
\hline
\end{tabular}
\caption{New York Heart Association Classification.}
\end{table}
Hypertension and myocardial infarction are the most common cause to CHF. Even though some studies indicate that the incidence of CHF can be expected to decrease, some scientists argue the opposite because mortality after acute myocardial infarction has decreased notably, which together with the growing elderly population will increase the incidence. Approximately 2% of the adult populations have CHF and the prevalence increases with age; 6-10% of people over the age of 65 years are affected. The economic burden of CHF to health service and society is substantial, accounting for about 2% of all health-care spendings. This is mostly due to the high admission rates, but the steady increase, in the age-adjusted rates of admission for CHF, seems to have reached a plateau lately.

Pharmacological and non-pharmacological management of CHF

The first goal of CHF treatment is prevention. The underlying cause should always be the first target for treatment, but when cardiac dysfunction is established progression of CHF needs to be prevented. The second goal is to maintain or improve quality of life and the third is to improve survival. According to both European and American guidelines the pharmacological treatment of CHF should consist of angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs) and, beta-blockers, with or without diuretics. Aldosterone antagonists and ARBs may be added in selected patients. The objective is to improve cardiac output, reduce the increased filling pressure in the heart and reduce the neurohormonal activation that is unfavourable to patients with CHF. The choice and combination of drugs are based on the severity, course and type of CHF. Since the co-morbidity is high among CHF patients other regimes such as treatment for arrhythmia and diabetes are common. Due to the complex pharmacological treatment, need for regular monitoring and necessary changes in life-style, the non-pharmacological treatment is an important part of the CHF therapy. For this purpose CHF programmes have developed all over Europe. Key components of these programmes are an adequate diagnosis, early follow-up after hospitalisation, optimising drug therapy and patient education and counselling. An increased access to care, provided by nurses, physicians or a multi-disciplinary team, has been shown to decrease mortality and hospital readmission, improve health-related quality of life and, in addition, is likely to reduce costs. Sweden was one of the first countries to establish nurse-led CHF programmes for patient education and follow-up after hospitalisation. In a survey in the year 1998, 69% of all hospitals in Sweden had nurse-led CHF clinics and in the year 2005 there were clinics in 81% of the hospitals.
Quality of life

Quality of life is a difficult concept to define and its interpretation depends on the scientific discipline of origin. Human existence and defining “the good life” is of concern to philosophers, ethicists debate quality of life in relation to “sanctity of life” and social utility, whereas economists are concerned with the priority of the resources of the society. Physicians are often focused on health- and illness-related variables, whereas nurses have a more holistic approach. Several have made an attempt to define quality of life and important components are the self-perceived satisfaction with life and sense of well-being. Since quality of life is a wide concept, health-related quality of life (HRQoL) is often used to assess aspects of an individual’s subjective experiences related both directly and indirectly to health, disability and impairment. The concept is originated from the constitution of the World Health Organisation, which defines health as: “a complete state of physical, mental, social well-being not merely the absence of disease or infirmity”. HRQoL can be measured by either generic or disease specific instruments. Generic scales are usually referred to as broader measures of health status, whereas disease specific scales aim to measure specific diseases and the effectiveness of treatment. It is recommended to use these type of scales in combination. Today there is a debate on whether HRQoL instruments are really measuring what they intend to measure, or if they measure self-perceived health status.

When asked about their everyday life persons with advanced CHF often mention the physically limitations as fatigue and lack of energy as the greatest influencer. This impacts the life in several ways, social isolation, anxiety and being a burden to others are some. However, if patients with CHF, with support from relatives and health-care professionals, can find acceptance and new ways to manage and cope, life can be worth living. When measuring HRQoL the findings are similar. Thus, even if the patient has a low level of HRQoL, the sense of coherence and the overall orientation toward demanding life situations can be the same as in healthy controls. Compared to other chronic conditions, e.g. obstructive pulmonary disease, arthritis and angina, HRQoL is lower in the CHF population. By individualised interventions nurses can improve HRQoL through education, support and exercise.

Patient education

Education of patients and relatives is an important part of the non-pharmacological management. Patient education can be defined as “a process of improving knowledge and skills in order to influence the attitudes and behaviour required to maintain or improve health”. Patient education is often delivered by nurses who are working in an
extended, autonomous nursing role. There is no consensus about a definition of a CHF nurse and the level, contents of training and education among these nurses vary in both Europe and the US. In Sweden most of the CHF nurses have a long experience of clinical practise (5 years or more) and have received additional education in CHF care, either at the hospital or through university courses. The CHF nurses are often well educated in the pathology, treatment and care of CHF, but training and education in teaching is often not provided. The goal of the patient education is to avoid deterioration of CHF by supporting the patient’s ability to recognise symptoms at an early stage, to providing knowledge on how to act when symptoms occur and when to seek medical aid. The first step of the teaching process is to identify and target the barriers of learning. Functional limitations due to reduced eyesight, impaired hearing and morbidity need to be assessed and the material used has to be adjusted to any such limitations. Cognitive deficits, especially with memory, attention, problem solving and concentration, are reported to be more frequent in patients with CHF. A recent meta-analysis of 3,000 individuals with CHF compared to 15,000 controls showed that the odds ratio for cognitive dysfunction was 1.62 (p <0.0001, CI 1.48-1.79) for patients with CHF. The most likely aetiology of cognitive deficits among patient with CHF is, an inadequate cerebral perfusion due to the insufficient circulation. This, naturally, affects learning and it must be taken into consideration, when choosing, for example booklets, which need to be short and clear. It can also be an advantage to divide the information in small segments with several repetitions. If there is a suspicion of cognitive deficits it is very important to involve relatives and other caregivers in the education, because it has been shown that social support positively effects knowledge. Other barriers that must be addressed are the occurrence of depression and low self-esteem, which can lead to low motivation to learn. There are many issues that need to be discussed with a patient with CHF and his/her family. The European Society of Cardiology has put together a list of topics to be used in the education of patients with CHF (Table 2).

In the patient education it is important to set realistic and achievable goals in order to motivate the patient to better self-care behaviour and adherence. It is equally important to continuously evaluate the goals and the progress in knowledge, in order to help the patient to actively participate in his/her own care and to make informed choices with competence and confidence.
Table 2. List of subjects to discuss with a CHF patient and his or her family.

<table>
<thead>
<tr>
<th>General advise</th>
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<tr>
<td>• Explain what CHF is and why symptoms occur</td>
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<td>• Causes of CHF</td>
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<td>• How to recognize symptoms</td>
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<tr>
<td>• Self-weighing</td>
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<tr>
<td>• Rationale of treatments</td>
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<tr>
<td>• Importance of adhering to pharmacological and non-pharmacological prescriptions</td>
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<tr>
<td>• Refrain from smoking</td>
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<td>• Prognosis</td>
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<tr>
<th>Drug counselling</th>
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<tbody>
<tr>
<td>• Effects</td>
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<tr>
<td>• Doses and time of administration</td>
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<tr>
<td>• Side effects and adverse effects</td>
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<tr>
<td>• Signs of intoxication</td>
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<tr>
<td>• What to do in case of missed doses</td>
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<td>• Self-management</td>
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<tr>
<th>Rest and exercise</th>
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<tr>
<td>• Rest</td>
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<td>• Exercise training</td>
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<tr>
<td>• Work</td>
</tr>
<tr>
<td>• Daily physical activity</td>
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<tr>
<td>• Sexual activity</td>
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<tr>
<td>• Rehabilitation</td>
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<tr>
<th>Dietary and social habits</th>
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<tbody>
<tr>
<td>• Restricted sodium intake when necessary</td>
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<tr>
<td>• Restricted fluid intake in severe heart failure</td>
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<tr>
<td>• Avoid excessive alcohol intake</td>
</tr>
<tr>
<td>• Smoking cessation</td>
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<td>• Reduce overweight</td>
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<tr>
<th>Vaccinations</th>
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<tr>
<td>• Pneumococcal and influenza immunisation</td>
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<tr>
<th>Travel</th>
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<tbody>
<tr>
<td>• Air flights</td>
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<td>• High altitude, hot/humid places</td>
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</table>
Adherence and self-care behaviour

Adherence and self-care can both be measured as outcomes in clinical practice and in research but they are also the means to improve other important outcomes such as quality of life, morbidity and mortality. It is essential to achieve satisfactory adherence and self-care knowledge. Several studies from the late 1990s found that patients had less than adequate knowledge about their CHF and its treatment. More recent research is focusing on adherence and self-care to evaluate different educational interventions, e.g. Riegel and Carlson, Gonzáles et al. and Evangelista et al. The concepts adherence and compliance are rather alike and are often used in a similar way. Compliance is the oldest word for how patients follow his/her treatment. In the mid-1970s Sackett and Haynes defined compliance as “the extent to which a person’s behaviour (in terms of taking medications, following diets or executing other lifestyle changes) coincides with medical or health advise” 53. This definition has been criticized for the lack of cooperation between the patient and health care providers, the patient are expected to obey. Therefore alternative terms such as adherence and concordance evolved. The most well-known is the World Health Organisation’s definition: “the extent to which a person’s behaviour-taking medication, follow[ing] a diet and/or executing lifestyle changes - corresponds with agreed recommendations from a health care provider” 54.

The main difference between compliance and adherence is generally considered to be that adherence requires the patients’ agreement to the recommendation and it is intended to be non-judgmental 55. A relatively new term is concordance and this concept is based on partnership where patient and health care providers are equal. The patient makes his/her own decisions and therefore he/she needs to be informed about different treatment options and the effects and side-effects attached to each option. Compliance is frequently used in medical research and often with the same underlying meaning as adherence. Since there is no consensus in the scientific community about which term to use, each researcher has to make a choice and in this thesis the term adherence will be used. This choice is made because the concept adherence is based on collaboration between the patient and the health-care provider and that the concept is widely used in both research and clinical practice. It is well known that adherence to prescribed medication is on average low, however recent research showed that among patients with CHF adherence to medication was high, over 80%.
Regarding adherence to the non-pharmacological treatment the findings varies a lot. In a review from 2005 61, 50-88% of the patients with CHF stated that they followed a sodium restricted diet and 23-37% restricted their fluid intake. Compliance with daily weighing ranged from 12-75% but the majority of the patients weighed themselves regularly. Nowadays advice about physical activity is recommended in CHF management programmes, but despite this advice, 41-58% did not follow this recommendation 61. Adherence and self-care are depending on each other. Orem describes self-care as an “action of mature and maturing persons who have developed the capability to take care of themselves in their environmental situation” and the purpose is “action that has pattern and sequences and, when performed effectively, contributes in specific ways to human structural integrity, human functioning, and human development” 62.

The facilitators and barriers to CHF self-care have been studied by Riegel & Carlson 43. The barriers include physical limitation, difficulties coping with treatment, lack of knowledge/misconceptions, distressed emotions, multiple comorbidities and personal struggles. Self-care involves the recognition of classic symptoms and following the treatment regimen. The strategies to adapt to a life with CHF involve practical adaptations and the use of internal and external resources. The authors conclude that motivation and counselling on the benefits of practicing self-care are important in CHF management and this approach with a motivational intervention has been tested in a small sample with promising results 63. Since knowledge, adherence and self-care are depending on each other it is difficult to evaluate the effects of the concepts separately, it is often management programmes that are evaluated. Reviews show that CHF management programmes results in a reduction of CHF-related readmissions and improvements in health-related quality of life 22, 64. One review that targeted self-care alone showed similar results in readmissions for CHF 10.

Thirst and fluid intake

Thirst is, besides breathlessness and/or fatigue and peripheral oedema, a symptom that patient with CHF often complain about during a hospital stay 7. Several factors can cause thirst. Firstly, the pathology of CHF, with a low cardiac output and increased activation of neurohormonal systems, stimulates the thirst centre in the hypothalamus. Secondly, diuretic therapy can induce xerostomia, which also stimulates the thirst centre 16, 65. Thirdly, the recommendation to restrict fluid intake can increase the perceived thirst. Thirst is described as the desire to drink by both physiological and behavioural cues, resulting from deficit of water 66. The physiological fluid requirement, for a healthy person, is 30-35 ml/kg body weight/day 65, but it is depending on
diet, environment and activity level. The water balance is a sensitive process and there is a need to maintain the body water content within narrow limits. Water losses of 2% of body mass lead to reduction in exercise test performance, and alertness and ability to concentrate declines.

Among healthy people who have an adequate nutrition, approximately 80% of total daily water intake is obtained from beverages and about 20% from food. For patients with CHF there is a risk of malnutrition due to insufficient diet and higher total energy expenditure, and this must be taken into account when daily fluid needs are estimated. The fluid recommendations given to patients with CHF today are general and do not take anything of this into account. It seems strange that a person with a body weight of 50 kg has the same fluid prescription as someone weighing 80 kg.

There is no scientific evidence in the literature for the recommendation to restrict the fluid intake. Formerly, when very little pharmacological treatment was available, fluid restriction was one of few interventional options. However, during the last decades the pharmacological treatment has improved considerably and, therefore should the recommendation to CHF patients to restrict the fluid intake should be reassessed and challenged scientifically.
AIMS

The overall aim of this thesis was to describe and evaluate self-care behaviour and to describe daily life experiences in patients with CHF, with special reference to fluid intake.

Specific aims were

- To (1) describe self-care with special regard to daily self-weighing and salt and fluid restriction in patients with HF in primary health care, during one year of monthly telephone follow-up after a single session education, (2) to describe gender differences in regard to self-care, and (3) to investigate if self-care was associated with health-related quality of life. (Paper I)

- To compare the effects of a restrictive to those of a liberal fluid prescription, on quality of life, physical capacity, thirst and hospital admissions, in patients who had improved from NYHA class (III-)IV CHF to a stable condition, without clinical signs of significant fluid overload. (Paper II)

- To describe the self-reported fluid intake and its effects on body weight, signs and symptoms of CHF, quality of life, physical capacity and thirst, in patients with stabilised CHF. (Paper III)

- To describe how persons with CHF experience and manage daily life. (Paper IV)
METHODS

Design and setting

In this thesis, methods to analyse both quantitative and qualitative data are used. The reason for this was that these data complement each other and generate different kinds of knowledge that is useful for nurses in clinical practise. The analysis of qualitative data emphasize understanding of the human experience as it is lived and narrated, whereas analysis of quantitative data are used to generalize the result of numeric information. An overview of the design of the studies, data collection, measurements and analysis are presented in Table 3.

Study I had a one-group, pre- and post-test design because the study was a subgroup analysis of a larger randomised trial performed between April 1999 to April 2000. Patients from four primary care centres in southern Sweden participated in the study. The nurse-led intervention programme was provided in the home of the patient and consisted of one intensive session with education and counselling at the beginning of the study. The written, verbal and interactive educational material used was based on guidelines and aimed to improve the patients understanding of CHF and self-care. At the time of enrolment, before the educational programme, clinical data were collected and self-care behaviour and quality of life were assessed. Three and twelve months after the education this was reassessed. Self-management regarding weighing, salt and fluid restriction, and the status of the patients, where evaluated through standardised telephone interviews. The telephone interviews were performed monthly except at three and twelve months, when the follow-up was done in the patients’ home. Approval was received from the Research Ethics Committee at Linköping University, Sweden. In order to meet the aim of present study, the items of interest were selected from the self-care behaviour scale and from the questions the telephone interviews (Table 4,5).
### Table 3. Overview of the studies in this thesis.

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<th>Study I</th>
<th>Study II</th>
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<th>Study IV</th>
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<td>Subjects</td>
<td>60</td>
<td>74</td>
<td>63</td>
<td>15</td>
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<tr>
<td>Recruited from</td>
<td>Primary healthcare</td>
<td>Hospital and</td>
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<td>out-patient CHF clinic</td>
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<td>Design</td>
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<td>Randomised controlled</td>
<td>Randomised controlled</td>
<td>Interview study.</td>
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<td>Secondary analysis</td>
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<td>Monthly follow-up during</td>
<td>32 weeks follow-up</td>
<td>32 weeks follow-up</td>
<td>Interview</td>
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<td>one year</td>
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<td>Measurements</td>
<td>EQ-5D</td>
<td>EQ-5D</td>
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<td>EHFScBS</td>
<td>MLWHF</td>
<td>MLWHF</td>
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<td>Telephone interview</td>
<td>Six-minute walk test</td>
<td>Six-minute walk test</td>
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<td></td>
<td>Questionnaire</td>
<td>VAS, sense of thirst and</td>
<td>VAS, sense of thirst and</td>
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<td>Protocol of the fluid</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>intake</td>
<td></td>
</tr>
<tr>
<td>Analysis</td>
<td>Within group comparison</td>
<td>Within-subject, between-</td>
<td>Between group comparison</td>
<td>Content analysis</td>
</tr>
<tr>
<td></td>
<td>Correlation</td>
<td>intervention comparison</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4. Selected items from the EHFScBS scale.

1. I weigh myself every day.
   I completely agree   I completely disagree
   ☐ ☐ ☐ ☐ ☐

2. I limit the amount of fluid I drink.
   I completely agree   I completely disagree
   ☐ ☐ ☐ ☐ ☐

3. I eat a low salt diet.
   I completely agree   I completely disagree
   ☐ ☐ ☐ ☐ ☐

Table 5. Items used from the monthly telephone interviews.

Body weight
1. How many times per week do you measure your weight?
Yes ☐ No ☐
2. Do you keep a record of your body weight?
☐ Unchanged
☐ Lost weight
☐ Gained weight
☐ Unsure
3. How has your body weight been the last month?
☐ Unchanged
☐ Lost weight
☐ Gained weight
☐ Unsure

Fluid intake
4. Do you restrict your fluid intake?
Yes ☐ No ☐
5. How was your fluid intake during the last month?
☐ Unchanged
☐ Increased
☐ Decreased
☐ Unsure

Studies II and III are based on the same trial, which had a randomised, cross-over design. In a cross-over trial the subjects are participating in more than one intervention. The randomisation was a 1:1 telephone randomisation and was carried out at the end of the inclusion visit. In intervention 1 the patients were recommended to adhere to a maximum fluid intake of 1.5L/day. The recommendation in intervention 2
was based on physiological fluid requirement of 30 ml/kg body weight/day and the fluid intake could be increased to a maximum of 35 ml/kg body weight/day. Each intervention period was 16 weeks long and during the entire 32-week study period the patients visited the study nurse 13 times (Fig. 1). Study III was a secondary analysis of Study II. During the entire study period the patients were instructed to measure and account for all fluid intake on a daily basis. The patients were divided into two groups based on the median fluid intake calculated in ml/kg bodyweight/day. The study was carried out at the Heart Failure Unit, Department of Cardiology, Malmö University Hospital and at the Heart Failure Unit, Department of Cardiology, Linköping University Hospital, Sweden between September 2002 to January 2005, and was approved by the Regional Ethics Committees of Human Research at the Universities of Lund (LU 166-02) and Linköping (Li 150-03).

**Enrolment**
Vital signs and symptoms, body weight, NYHA classification, sense of thirst, quality of life, physical capacity.
Randomisation into intervention 1 or 2

↓

**Week 1, 3, 5, 8, 12**
Vital signs and symptoms, body weight and sense of thirst at week 8

↓

**Cross-over week 16**
Vital signs and symptoms, body weight, NYHA classification, sense of thirst, quality of life, physical capacity

↓

**Week 17, 19, 21, 24, 28**
Vital signs and symptoms, body weight and sense of thirst at week 24

↓

**End of study week 32**
Vital signs and symptoms, body weight, NYHA classification, sense of thirst, quality of life, physical capacity

*Fig. 1. Flow chart describing contents and the time between visits in study II,III.*
In Study IV the technique used was semi-structured interviews with focus on food and beverage, activity, relations and state of mind. In this thesis the interviews was used to encourage the participants to define the important dimensions of living with CHF. The study was approved by regional Ethics Committee for Human Research in Lund (LU 966-03), Sweden and performed during the years 2004-2005.

Subjects
In all four studies, enrolled patients had to have typical signs and symptoms of CHF. In Study 1, patients had to have diagnosed CHF based on echocardiography (left ventricular ejection fraction below 45%) and/or radiographic evidence of pulmonary congestion. In study II-IV, a left ventricular ejection fraction below 45% at echocardiography was required. In Study I patients were required to be over the age of 18 years, to be in NYHA class II-IV, and to reside within the catchment area. Furthermore, in studies II-III, the patients were required to be in a stable condition without clinical signs of significant fluid overload, and in Study IV the diagnosis had to have been verified for at least 2 years before inclusion. Exclusion criteria for all the studies were other severe mental or physical disease, difficulties to understand or read the Swedish language and participation in another clinical trial. In Study I patients were excluded if they were to be followed-up at a hospital based CHF clinic. In studies II-III additional exclusion criteria were: bodyweight below 65 kg, unlikely to comply with the study interventions, and needing fluid restriction due to other severe illness, were added. Experienced CHF nurses were involved in the screening of eligible participants. Eligible patients received verbal and written information about the studies and informed consent was obtained prior to study start. Drop-outs throughout the follow-up periods of studies I-III are described in Table 6.

Table 6. Reasons for drop-outs during the follow-up periods.

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death</td>
<td>10</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Other severe disease</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withdrew consent</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Inability to comply with study protocol</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>
Study II had an intention-to-treat design. However, due to the cross-over design only data from patients who completed both interventions was analysed. In Study III all the eleven patients that dropped out, due to incomplete fluid protocol, were excluded from the analysis. In Study IV a purposive sampling technique was used. The nurses involved in the screening process were instructed to look for typical cases who would meet the inclusion criteria, according to their judgement. The baseline characteristics of patients included in the studies are described in Table 7.

Table 7. Characteristics of patients in studies I-IV

<table>
<thead>
<tr>
<th></th>
<th>Study I (n=60)</th>
<th>Studies II-III (n=74)</th>
<th>Study IV (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean±SD</td>
<td>79±7</td>
<td>70±10</td>
<td>74±7</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>31 (52%)</td>
<td>62 (84%)</td>
<td>13 (87%)</td>
</tr>
<tr>
<td>Women</td>
<td>29 (48%)</td>
<td>12 (16%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>NYHA class, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>3 (4%)</td>
<td>65 (88%)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>II</td>
<td>24 (40%)</td>
<td>3 (4%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>III</td>
<td>27 (45%)</td>
<td>6 (16%)</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>IV</td>
<td>9 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-morbidities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>39 (65%)</td>
<td>54 (73%)</td>
<td>11 (73%)</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>21 (35%)</td>
<td>40 (54%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>23 (38%)</td>
<td>17 (23%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>15 (25%)</td>
<td>19 (26%)</td>
<td></td>
</tr>
</tbody>
</table>

NYHA class, New York Heart Association Classification.
SD-standard deviation

Data collection

Different kinds of methods were used to collect data in this thesis. Data from questionnaires to evaluate health-related quality of life and self-care behaviour (studies I-III), as well as physical assessments (studies II-III) and interviews (Study IV), were provided by the patients. Data concerning the patients’ medical and social situation, and number of hospitalisations, days in hospital and deaths were assessed from the hospital charts (studies I-IV).
Measurements

Quality of life

Two instruments were used in this thesis to measure quality of life. EuroQol (EQ-5D) is a measure of self-perceived health status and it consists of two parts (studies I-III). The first part is a descriptive system that defines 5 health dimensions; morbidity, self-care, usual activity, pain/discomfort and anxiety/depression. In response to each question, the patients are asked to choose one of three levels: no problem (coded as 1), some or moderate problems (coded as 2) and unable or extreme problems (coded as 3). The scores from each dimension are put together to a 5-digit number that represent the overall health state. Each of the 243 possible health states has a preference value or score obtained from a sample of the general population. This preference value can range from -0.59 (worst possible health) to 1 (best possible health). The second part is a visual analogue scale (VAS), where zero denotes worst possible health and 100 best possible health. Responsiveness, validity and reliability have been tested with satisfying results in different populations.

The Minnesota Living with Heart Failure Questionnaire (MLWHF) is a disease-specific instrument, consisting of 21 items (studies II-III). The questionnaire was designed to measure the patients’ perceptions of the effects of CHF on their daily life. Physical, psychological and socioeconomic impairments are in focus and the patients respond on a 6-point scale, ranging from 0-5 and the total score can vary between 0-105. A low score indicate better quality of life. The specific impairments, e.g. symptoms, morbidity, everyday activities, relationships and depression, are listed according to how much each prevents the patients from living as they want. Internal consistency reliability measured by Cronbach’s alfa has been shown to be high, ranging from 0.91 to 0.96. Face validity has been judged as good. The MLWHF is recommended to be used in non-pharmacological interventions, but it has been shown that the intensity of the intervention needs to be high. This version has also been tested in an elderly population with good results and is therefore recommended for research and clinical use.

Self-care behaviour

The European Heart Failure Self-Care Behaviour Scale (EHFScBS) is a 12-item questionnaire (Study I). The score from each item ranges from 1 (I completely agree) to 5 (I completely disagree). A total score of 12 indicates the best possible self-care behaviour, whereas 60 indicates the lowest self-care behaviour. The questionnaire has been tested for reliability and validity in Sweden, Italy, United Kingdom and the Netherlands, and internal consistency reliability measured by Cronbach’s Alpha.
range from 0.69 to 0.93. In Study I, three items of interest were selected (see Table 4) and the patients were considered to be adherent at a score of 1-2 and not adherent at a score of 3-5. The items of interest were also selected from the standardised telephone interviews (see Table 5). The questionnaire was developed for this study and aimed to probe for self-care management. In the process of developing the questionnaire, an expert panel of experienced primary health care nurses, physicians, CHF nurses and cardiologists were involved to establish face validity.

**Thirst and the difficulties to adhere to the fluid prescription**

At the time of planning studies II-III no specific instrument was found to measure thirst. Since thirst is a subjective sensation, like for instance pain, the VAS was an option. VAS is often used to evaluate pain but it has also been used to measure thirst in studies in patients with cancer and renal failure. The scale was a 100 millimetre long horizontal line and was marked on the left side with no thirst (0) and on the right side with constant thirst (100). The same type of scale was used to estimate the difficulties to adhere to the fluid prescription, and this was marked on the left side with “no problem” and on the right side with “tremendous problems”. An expert panel of nurses and cardiologists was used to determine face validity and it was tested in 15 patients. Before using the VAS, some small adjustments were made based on the recommendations from the patients and then the VAS was re-tested.

**Physical capacity**

In studies II-III the six-minute walk test was used to measure submaximal physical performance. The test is simple and safe and is recommended for use in both trials and in clinical evaluation of CHF. In our study, changes in symptoms were of interest and the six-minute walk test has been shown to be concordant with changes in symptoms. The walk test was performed in a secluded corridor and the length of the course was 30 metres. The instruction were to walk as far as possible during the six minutes and if necessary stop to rest. No conversation or encouragements were given during the walk.

**The interviews**

The interviews were carried out in a secluded office at the hospital. To assure privacy, the phone was switched off and the door secured. The interview was intended to be a dialogue between the interviewee and the interviewer and the informant was to feel free to express any experiences of his/her CHF and any effects of the CHF on daily life. An interview guide was developed to encircle the areas of special interest and this guide was shown to the informant before the interview. Four areas of interest
were identified; food and beverage, activity, relations and state of mind. The interview guide was tested in one interview and after that some minor adjustments were made concerning the order of the areas of interest. Open-ended questions were used as technique in the interviews. The opening question was ‘Could you please tell me about you experiences of living with CHF?’ Follow-up questions like ‘Can you tell me more about that?’, ‘How did you handle that?’ and ‘How did you feel then?’ were asked to elucidate the experiences and strategies used to cope with the disease. The interviews were tape-recorded, transcribed verbatim including non-verbal expressions like silence, crying and laughter. All interviews were performed by the same person (MH) and they lasted between 23 and 60 minutes.
ANALYSIS

Sample size calculation (studies II-III)
The primary variable for estimating statistical power was self-perceived health status according to the EQ-5D VAS. An improvement of 10% of the EQ-5D VAS score was considered to be clinically significant. If the studies would have an 80% power at the 5% significance level to detect a 15% absolute between-intervention difference 59 patients were required in each intervention (=118). Due to the cross-over design used, each patient participating in both interventions, this number could be halved (=59). In order to compensate for an expected 20% drop out rate, 74 patients were included. There was also power to detect a reduction in total hospitalisation.

Statistical analysis (studies I-III)
All analyses were performed using the SPSS® (version 12.0) statistical program. Descriptive analyses were used to describe the sample and the response in the study variables. Quality of life, self-care, thirst, the difficulties to adhere to the fluid prescription, hospital admissions and days spent in hospital were, due to scale level, expressed as median [interquartile range] and analysed by non-parametric statistical methods. Fluid intake in Study III is described both as mean ± SD and median [interquartile range]. To detect differences between groups, the Mann-Whitney U test was used (Study III). For comparisons within-subjects, i.e. between-interventions, the Wilcoxon matched pair test was applied (studies I-II). For associations the Spearman rank correlation test was used (Study I). For analysis of six-minute walk test and weight data, Student’s t-test was used. Chi-Squared test was used for analysis of symptoms. P<0.05 denotes statistical significance. In Study II, analyses were made to detect carry-over effects according to the recommendations given by Altman for cross-over trials. Very little data were missing in studies II and III. In Study I, missing data were, depending on the type and quality of the data, either estimated or eliminated from the analysis. Some estimations were made regarding fluid intake.
(studies II-III); if data was missing the mean fluid intake from the week before was used.

**Qualitative data (Study IV)**

The text from the interviews was analysed using manifest and latent content analysis. Content analysis is a subjective and systematic approach with the purpose to describe life experiences and give them meaning. Berg describes the manifest content analysis as being “comparable to the surface structure present in the message” and the latent content analysis is “the deep structural meaning conveyed by the message”.

The analysing process started with that the text was read and re-read in order to become immersed in the data and essential features from each interview were summarised in short memos in order to acquire a sense of the whole. After that, the search for meaning units began and the selected meaning unit reflected on how the informants experienced and managed their daily life. In the process to convey the deep structural meaning, three questions were asked to the meaning units; “What is this about?”, “What does it mean?” and “What effects does it have?”. This generated a number of sub-themes that were counted, judged and reflected on, in terms of the extent to which they fitted together or differed from each other. The sub-themes were then organised into themes that covered, on an interpretative level, the underlying meaning of the text, and the question “How” was to be answered by the theme. To ensure credibility, all interviews were independently analysed by two authors (MH, ML). The frequent discussions during the analysing process lead to consensus so that the experiences of living with CHF remained as true to the original as possible. In the later part of the analysis, all authors were participating.

To achieve trustworthiness in qualitative research it is important to describe the credibility, dependability, confirmability and transferability of the study. According to Polit and Hungler credibility refers to how well data and processes address the intended focus of the study. The areas that need to be addressed regarding credibility are; selection of context, selection of informants, selection of the most suitable meaning units and how well categories and themes cover data. Dependability refers to in what degree the data change over time and alterations made in the researcher’s decisions during the analysis process. Confirmability refers to analysis of the data in an objective and neutral way e.g. that two or more persons analyse and agree on the findings. Transferability refers to “the extent to which the findings can be transferred to other settings or groups”. To achieve transferability, the context and culture, selection
and characteristics of the informants, and data collection and process of analysis must be clear and distinctly described.
ETHICAL CONSIDERATIONS

Since all studies in this thesis involve patients the studies have been conducted according to the Declaration of Helsinki. The Declaration of Helsinki states that the participants must be volunteers and well informed of the study. All patients received both written and verbal information about the study they were asked to participate in and it was made very clear that they could withdraw their consent without any explanation or reprisal. All data were kept in a secure office so that no unauthorized person could examine the data, and by this confidentiality was, as far as possible, guaranteed. In studies II-III there was a potential risk of an impaired health-status due to fluid overload, but since we had a close follow-up in the study we believed that the risk did not outweigh the importance of the objectives. In an interview (Study IV) there is always a risk that the informants experience negative emotions. But the impression was, despite that few of the informants cried during the interview, that no negative emotions arose. Permission was obtained from the Regional Ethics Committees for Human Research at the universities participating, and the studies were performed according to principals of autonomy, beneficence, not harming, justice and with respect for the protection of human rights.
RESULTS

Quality of life and self-care behaviour after a single session education of patients with CHF in primary health care (Study I)

The 60 patients participating in the study had a high mean age of 79±7 years. The distribution between men and women was even and 94% of the patients were in NYHA class II or III. No significant changes or associations were found regarding self-perceived health status measured by EQ-5D and self-care behaviour measured by EHFScBS. The only gender difference found was that men, but not women, decreased their self-care behaviour between 3 and 12 months (p=0.012). No significant difference was found in quality of life between the genders. The majority of the patients measured their body weight once a week or more and the mean for the whole follow-up period was 3 times/week. Before the education 30% stated that they weighed themselves daily and weighing behaviour was exactly the same after 3 month, but improved slightly to 40% after 1 year. Only one fifth of the patients made a written record of the body weight and, consequently, very few could answer the question if they noticed any change in their body weight. No gender differences were found regarding weighing behaviour and no associations were found between adherence to weight control and gender, age, NYHA class or education level. In all, 70% of the patients stated that they adhered to the fluid prescription and this remained stable throughout the study period. There were no differences between men and women in this regard. A few patients reported that they had made some adjustments of the fluid intake during the first month but this must be interpreted with some caution since rather few patients answered this question. At baseline 50% of the patients claimed that they were adhering to the salt recommendation and this did not change throughout the study period. No gender difference was found in this regard. No significant associations were found between adherence to fluid or salt restriction and the background variables.
Liberal versus restricted fluid prescription (Study II)

Out of the 74 patients randomised, 36 were randomised to intervention 1 (1.5 L fluid/day) and 38 were randomised to intervention 2 (fluid intake corresponding to 30ml/kg body weight/day). Due to cross-over design, between-intervention analyses were based on within-subject comparisons. Therefore, only data from patients completing the study were analysed (Table 8).

There were no significant differences between the patients in the two interventions regarding demographics and clinical characteristics at the respective baselines. The only significant difference between the whole study population and the patients that did not complete the study was that more patients were in NYHA class III among the drop-outs (33% versus 8% in the total study population, P= 0.01). All patients were in NYHA class I-II, except six patients (16%) who were in NYHA class III. Only 16% of the study population was women. The patients were well treated pharmacologically and the prevalence of co-morbidities was high. All cardiovascular medication, including diuretics, was virtually unchanged during the study in both interventions.

No carry-over effects between the two interventions were found in the analysis of EQ-5D, MLWHF or six-minute walk test, but carry-over effects existed in sense of thirst and the difficulties to adhere to the fluid prescription. At the end of the two interventions, there were no significant between-intervention differences in the analysis of EQ-5D, MLWHF, six-minute walk test or bodyweight (Table 9). No significant differences were found in renal function, electrolytes, haemoglobin and vital signs between interventions. There were significantly less sense of thirst and the difficulties to adhere to the fluid prescription at the end of intervention 2 compared to the end of intervention 1 (Table 9).

In total there were twelve readmissions to hospital due to CHF during the follow-up period. One patient was readmitted two times during each intervention. The distribution between the interventions was the same, 6 readmissions during the 1.5L/day intervention and 6 during the 30ml/kg body weight/day intervention. The number of days spent in hospital was 42 during the 1.5L/day intervention and 56 during the 30ml/kg body weight/day intervention (P=0.30). Analysis of carry-over effects, in regard to the order of the interventions, revealed no such effects.
Table 8. Demographics and clinical characteristics of the study sample at the beginning of each intervention (Study II).

<table>
<thead>
<tr>
<th></th>
<th>1.5L/day intervention (n=65)</th>
<th>30ml/kg/day intervention(n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, mean±SD</strong></td>
<td>70 ± 10</td>
<td>70 ± 10</td>
</tr>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>54 (83%)</td>
<td>54 (83%)</td>
</tr>
<tr>
<td>Women</td>
<td>11 (17%)</td>
<td>11 (17%)</td>
</tr>
<tr>
<td><strong>Vital signs and symptoms</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bodyweight (kg), mean±SD</td>
<td>87 ± 15</td>
<td>87 ± 15</td>
</tr>
<tr>
<td>Heart rate, mean±SD</td>
<td>70 ± 10</td>
<td>70 ± 11</td>
</tr>
<tr>
<td>Systolic blood pressure (mmHg), mean±SD</td>
<td>119 ± 17</td>
<td>118 ± 15</td>
</tr>
<tr>
<td>Diastolic blood pressure (mmHg), mean±SD</td>
<td>69 ± 9</td>
<td>71 ± 10</td>
</tr>
<tr>
<td><strong>Blood samples</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haemoglobin g/L, mean±SD</td>
<td>137 ± 15</td>
<td>135 ± 16</td>
</tr>
<tr>
<td>Na⁺ mmol/L, mean±SD</td>
<td>140 ± 3</td>
<td>140 ± 2</td>
</tr>
<tr>
<td>K⁺ mmol/L, mean±SD</td>
<td>4.2 ± 0.4</td>
<td>4.3 ± 0.3</td>
</tr>
<tr>
<td>Creatinine, mean±SD</td>
<td>121 ± 50</td>
<td>120 ± 43</td>
</tr>
<tr>
<td><strong>NYHA class, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>4 (6%)</td>
<td>4 (6%)</td>
</tr>
<tr>
<td>II</td>
<td>56 (86%)</td>
<td>55 (85%)</td>
</tr>
<tr>
<td>III</td>
<td>5 (8%)</td>
<td>6 (9%)</td>
</tr>
<tr>
<td><strong>Co-morbidities, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>48 (74%)</td>
<td>48 (74%)</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>33 (51%)</td>
<td>33 (51%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>17 (26%)</td>
<td>17 (26%)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>16 (25%)</td>
<td>16 (25%)</td>
</tr>
<tr>
<td><strong>Pharmacotherapy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diuretics</td>
<td>62 (96%)</td>
<td>62 (96%)</td>
</tr>
<tr>
<td>ACE-inhibitors</td>
<td>51 (78%)</td>
<td>51 (78%)</td>
</tr>
<tr>
<td>Beta- blockers</td>
<td>55 (85%)</td>
<td>56 (86%)</td>
</tr>
<tr>
<td>Spironolactone</td>
<td>28 (43%)</td>
<td>28 (43%)</td>
</tr>
<tr>
<td>Digitalis</td>
<td>19 (29%)</td>
<td>19 (29%)</td>
</tr>
</tbody>
</table>

*NYHA class - New York Heart Association Classification, SD - standard deviation.*
Table 9. Results at the end of each intervention. (N=65)

<table>
<thead>
<tr>
<th></th>
<th>End of the 1.5 L/day intervention</th>
<th>End of the 30ml/kg/day intervention,</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5D, median [IQR]</td>
<td>0.80 [0.66-0.92]</td>
<td>0.80 [0.70-0.92]</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td>(n=63)</td>
<td>(n=63)</td>
<td></td>
</tr>
<tr>
<td>EQ-5D VAS, median [IQR]</td>
<td>70 [55-85]</td>
<td>70 [57-82]</td>
<td>0.88</td>
</tr>
<tr>
<td></td>
<td>(n=63)</td>
<td>(n=63)</td>
<td></td>
</tr>
<tr>
<td>Minnesota Living with Heart Failure, median [IQR]</td>
<td>20 [11-40]</td>
<td>17 [9-44]</td>
<td>0.95</td>
</tr>
<tr>
<td></td>
<td>(n=64)</td>
<td>(n=64)</td>
<td></td>
</tr>
<tr>
<td>Six minute walk test, mean ±SD</td>
<td>407 ± 123</td>
<td>410 ± 119</td>
<td>0.59</td>
</tr>
<tr>
<td></td>
<td>(n=58)</td>
<td>(n=58)</td>
<td></td>
</tr>
<tr>
<td>Sense of thirst (VAS), median [IQR]</td>
<td>51 [16-69]</td>
<td>23 [6-53]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>(n=64)</td>
<td>(n=64)</td>
<td></td>
</tr>
<tr>
<td>Difficulties to adhere to the fluid prescription (VAS), median [IQR]</td>
<td>23 [5-56]</td>
<td>6 [1-24]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>(n=64)</td>
<td>(n=64)</td>
<td></td>
</tr>
<tr>
<td>Bodyweight kg, mean ±SD</td>
<td>87.1 ± 17</td>
<td>87.5 ± 18</td>
<td>0.718</td>
</tr>
</tbody>
</table>

IQR- interquartile range; SD- standard deviation; VAS- Visual Analogue Scale
Description of self-reported fluid intake and its effects (Study III)

In this study 63 patients contributed with data and their baseline demographics and characteristics are shown, by groups, in Table 10.

<table>
<thead>
<tr>
<th></th>
<th>&lt; 19 ml/kg/day (n=63)</th>
<th>≥ 19 ml/kg/day (n=63)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>67 ± 10 (33-85)</td>
<td>71 ± 9 (33-86)</td>
<td>0.029</td>
</tr>
<tr>
<td>Body weight (kg)</td>
<td>94 ± 15 (70-123)</td>
<td>81 ± 13 (65-123)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>BMI (kg/m²)</td>
<td>29.8 ± 4 (23-37)</td>
<td>26.3 ± 3 (21-35)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>P-Creatinine</td>
<td>121 ± 47 (70-339)</td>
<td>115 ±39 (46-268)</td>
<td>0.358</td>
</tr>
<tr>
<td>Women</td>
<td>8 (13)</td>
<td>14 (22)</td>
<td>0.159</td>
</tr>
<tr>
<td>NYHA, I / II / III</td>
<td>1 (3)/32 (94)/1 (3)</td>
<td>2 (7)/25(86)/2(7)</td>
<td>0.566</td>
</tr>
<tr>
<td>IHD</td>
<td>46 (73)</td>
<td>44 (70)</td>
<td>0.693</td>
</tr>
<tr>
<td>AMI</td>
<td>29 (46)</td>
<td>33 (52)</td>
<td>0.476</td>
</tr>
<tr>
<td>Hypertension</td>
<td>15 (23)</td>
<td>15 (23)</td>
<td>1.000</td>
</tr>
<tr>
<td>DM</td>
<td>20 (32)</td>
<td>12 (19)</td>
<td>0.176</td>
</tr>
<tr>
<td>Diuretics</td>
<td>60 (95)</td>
<td>60 (95)</td>
<td>1.000</td>
</tr>
<tr>
<td>ACEi</td>
<td>50 (79)</td>
<td>50 (79)</td>
<td>1.000</td>
</tr>
<tr>
<td>Beta-blocker</td>
<td>55 (87)</td>
<td>53 (84)</td>
<td>0.611</td>
</tr>
<tr>
<td>Spironolactone</td>
<td>25 (40)</td>
<td>25 (38)</td>
<td>1.000</td>
</tr>
<tr>
<td>Digitalis</td>
<td>20 (32)</td>
<td>16 (25)</td>
<td>0.430</td>
</tr>
</tbody>
</table>

NYHA - New York Heart Association classification; IHD - ischaemic heart disease; AMI - acute myocardial infarction; DM - diabetes mellitus; ACEi - angiotensin-converting enzyme inhibitor; SD - standard deviation.

The mean fluid intake during the 1.5L/day intervention was 17ml/body weight/day irrespective of period and during the 30ml/kg body weight/day it was 23 ml/kg body weight/day, also irrespective of period. The analyses in this study are based on groups by median fluid intake, 19 ml/kg body weight/day, calculated from the whole study period, regardless of the originally interventions groups. Each patient contributed with data twice; at the end of each study period. Each patient could belong to either of the two groups (below or at/above median) in each study period, depending on the actual
fluid intake of the patient during the respective period. The mean difference between the below and at/above median fluid intake groups was 8 ml/kg body weight/day. For a person with a body weight of 80 kg this means a difference in fluid intake of 640 ml/day (Table 11).

**Table 11. Description of the fluid intake, ml/kg body weight/day (N=63).**

<table>
<thead>
<tr>
<th>Fluid intake</th>
<th>Entire study period</th>
<th>&lt; 19 ml/kg/day</th>
<th>≥19 ml/kg/day</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean ±SD</td>
<td>20 ±5 (n=126)</td>
<td>16 ±2 (n=63)</td>
<td>24 ±3 (n=63)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Median [IQR]</td>
<td>19[15-23] (n=126)</td>
<td>16[14-17] (n=63)</td>
<td>23[21-26] (n=63)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

*Between groups.

The percentage change from baseline to study end in EQ-5D (p=0.788), EQ VAS (p=0.629), MLWHF (p=0.794) or in the six-minute walk test (p=0.870) did not differ significantly between the groups. The changes in signs and symptoms, such as body weight, peripheral oedema and pulmonary rales were small and no statistically significant differences were to be found. The diuretic therapy did not differ significantly between the groups. However, changes in sense of thirst and in difficulties to adhere to the fluid prescription showed significantly improvement in the above 19 ml/kg body weight/day group, as compared with the below median group (Table 12).

**Table 12. Measured changes in thirst and difficulties to adhere to the fluid prescription, in percentage, by median fluid intake.**

<table>
<thead>
<tr>
<th>Changes in sense of thirst (%), median [IQR]</th>
<th>&lt; 19 ml/kg/day</th>
<th>≥19 ml/kg/day</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in difficulties to adhere to the fluid prescription (%)</td>
<td>20 [-47 to 479] (n=60*)</td>
<td>24 [-89 to 47] (n=63*)</td>
<td>0.005</td>
</tr>
</tbody>
</table>

* Complete data on thirst and the difficulties to adhere to the fluid prescription are missing in some patients. Due to the cross over design, the analyses were performed on data from all patients during each 16 week study period, i.e. each patient contributed with data twice.
The experiences of living with CHF (Study IV)

Ten out of the fifteen interviewed persons were married, four were widows/widowers and one was living alone. All except one were retired and the duration of illness ranged between two and fifteen years. The analysis of the text revealed that the experiences of living with CHF can be interpreted as forces that either hinder or facilitate the person to live the life he/she wants. Forces in this sense mean personal and physical abilities and social factors that affect the way a person with CHF manage daily life.

The theme **hindering forces in daily life** illuminates by five sub-themes (Table 13). The most evident sub-theme was **limitations affecting daily life** and this entailed the difficulties to perform daily activities. The feelings of vulnerability and powerlessness led to that the informants did not have the strength to do the thing they used to do at home. It also meant isolation from family and friends so loneliness was a common feeling. Thirst and lack of appetite were also described as limiting. **Lack of knowledge** led to a feeling of ignorance and insecurity. It often gave utterance of not understanding the connection between the failing heart and the symptoms. **Inability to live up to expectations** from others and from themselves was expressed as hindering and it gave a feeling of incapacity and uncertainty. The second most expressed sub-theme was **inability to maintain control in life**, which meant losing control of bodily functions and changes in mood and temper. This led to an experience of identity crisis when the informants did not recognise themselves. **Dependence on others** also had a meaning of some sort of identity crisis, but the feelings related to this sub-theme were the experiences of being inferior and being a burden to the relatives.

<table>
<thead>
<tr>
<th>Hindering forces in daily life</th>
<th>231</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limitations affecting daily life</td>
<td>105</td>
</tr>
<tr>
<td>Lack of knowledge</td>
<td>22</td>
</tr>
<tr>
<td>Inability to live up to expectations</td>
<td>27</td>
</tr>
<tr>
<td>Inability to maintain control in life</td>
<td>47</td>
</tr>
<tr>
<td>Dependence on others</td>
<td>30</td>
</tr>
</tbody>
</table>

Table 13. Number of citations of theme and sub-themes.
Facilitating forces in daily life is the theme that illuminates the willpower of and the strategies used by the informants in their strive to be able to live a decent life (Table 14). Ability to understand was the search for an explanation or a reason why they had been stricken with heart disease. Several strategies were used; asking friends and health-care professionals for information and sharing experiences with people in the same situation were some that could enable the informants to value life in a positive way. Ability to accept the new situation in life was a strongly expressed sub-theme. It had a lot to do with realising, to be realistic and accept the limitations that occur. Finding happiness in small things, thinking positive thoughts and finding peace played an important role in gaining confidence in the new life situation. The more practical ways to cope with daily life was enlightened in the sub-theme finding other ways to handle life. To do daily tasks in small steps and putting up realistic goals day by day were often mentioned. It was very obvious in the text that the informants were optimistic about the future and willing to enjoy life, despite all nuisances the disease entails.

Table 14. Number of citations of theme and sub-themes.

<table>
<thead>
<tr>
<th>Facilitating forces in daily life</th>
<th>246</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ability to understand</td>
<td>45</td>
</tr>
<tr>
<td>• Ability to accept the new situation in life</td>
<td>100</td>
</tr>
<tr>
<td>• Finding other ways to handle life</td>
<td>101</td>
</tr>
</tbody>
</table>

As shown by tables 13 and 14 the distribution between the themes is fairly equal and the interpretation of this can be that, despite the difficulties persons with CHF face they are able to accept and adjust to a life with CHF.
DISCUSSION

Result discussion
The overall aim of this thesis was to describe and evaluate self-care behaviour and to describe daily life experiences in patients with CHF, with special reference to fluid intake. In essence, when compared with a restricted fluid intake of 1.5L/day, a higher fluid intake showed no effects on quality of life, physical capacity, hospital admissions or signs and symptoms of CHF, with the important exceptions that thirst and difficulties adhering to the fluid prescription were significantly decreased. The results regarding adherence, self-care behaviour and daily life experiences correspond well with results from other studies.

One third of the patients in Study I weighed themselves every day and on average patients measured body weight three times a week. This correspond well to other studies 47, 99 and may be considered satisfactory. Some interventional studies have reported adherence to daily weighting to be 75% 100, 101. It is difficult to know why these studies were so successful. In the study from de Lusignan et al. 100 only 10 patients participated in the interventional group and in the study by Strömberg et al. 101 the intervention was more intense and the measurements were different than in the study presented in Study I. One study 102, very similar to Study I in terms of setting and design, reported that the daily weighing behaviour increased to 94% in the intervention group. However, age differed, which is important. The patients in the study by Caldwell et al. 102 were 10 years younger than the patients in Study I and this is important, since various degrees of cognitive deficits are common in patients with CHF and increase with age 46. In elderly patients it could be an advantage to have a written record of body weight, both for the patient and for the healthcare professionals who are responsible for the care of the patient. However, in stable patients with CHF it may be sufficient to measure weight three times a week and it is gratifying that the best results regarding weighing behaviour are from the most recent studies.
In Study I 60% of the patients stated that they were adhering to salt restriction, which correspond fairly well to other studies reporting adherence ranging from 50% to 88% \(^{61}\). Adherence to fluid restriction is less investigated and the results are varying. In Study I, 70% of the patients stated that they followed the advice given to be restrictive with fluid intake, and this is in agreement with the results from van der Wal et al \(^{60}\). In that study, 73% stated that they adhered to the recommended fluid restriction, and 39% of them reported problems related to the fluid restriction, the most common problem was thirst. Other studies have reported a lower adherence 23-37% \(^{61}\). Maybe this is also an age issue since elderly people often drink less due to diminished sensation of thirst \(^{66}\). The interpretation of the overall self-care behaviour measured by EHFScBS must be that the patients’ self-care behaviour is rather good with a mean score of 29 at the end of the study. The patients are considered to be adherent at score 1-2 there are some items that have a higher score. In clinical practice these items, based on the individual, should be the target for the patient education. The EHFScBS was developed for research purposes, but with additional testing the scale can be a useful tool to identify specific educational and counselling needs \(^{87}\).

A fluid intake recommendation of 30ml/kg bodyweight/day may in reality be a free fluid intake for most individuals. In Study II, the assessment of the self-reported fluid intake in the individualised intervention revealed a mean fluid intake of 23 ml/kg body weight/day (SD±4). This corresponds to a 6 ml/kg body weight/day higher fluid intake than in the 1.5/day intervention. For a person weighing 87 kg (average in Study II) this means that the fluid intake increased by 500 ml/day to 2L/day. If the fluid in food is added to this, i.e. approximately 20% of the total fluid intake, the total fluid intake would be 2.4L/day. This is the same as in water balance studies for resting and starving adult men, but these studies also indicate that, if modest physical activity is performed, the water intake requirements increase to approximately 3.2L/day. Limited data are available for women, but it has been indicated that the fluid requirements are lower in women because they are physically smaller and have lower metabolic expenditures \(^{66}\). Our interpretation of Studies II and III are on the average patient in the studies. Since no negative effects of a more liberal and individualised fluid intake recommendation were found in hospital admissions, physical capacity, diuretic use, symptoms and signs of CHF, this could be a useful way of reasoning when healthcare professionals are discussing fluid intake with a patient with stable CHF. The fluid restriction in CHF treatments is also questioned by Travers et al. \(^{103}\). The aim in that study was to examine the clinical effects of fluid restriction in patients admitted to the hospital with class IV CHF. The results showed no significant differences between the group that had fluid restriction of 1 L/day and the group that
had no restriction, in time to clinical stability or in time to discontinuation of intravenous diuretic therapy. The mean fluid intake in the free fluid group was very close to 1.5 L/day but the patients weighed on average 10 kg less than the patients in our study, so calculated as ml/kg body weight/day for the average patient the fluid intake was 19ml/kg body weight/day. Larger trials are needed to confirm these findings, but the results from our study and the study by Travers et al.\textsuperscript{103} indicate that the necessity of fluid restriction in patients with CHF is questionable. Instead of routinely advising patients to be restrictive with fluid intake, nurses involved in the care of patients with CHF could limit these restrictions to risk-patients, such as patients with hyponatremia, renal failure and those who have abnormally high fluid intake.

The most important findings of Studies II and III, not surprisingly, were that thirst and difficulties to adhere to the fluid prescription decreased significantly when the patient had a higher fluid intake. Other problems that may also be expected to improve with increased fluid intake are xerostomia, altered taste and impaired dental health and this needs to be examined in future studies. Health-related quality of life and physical capacity did not improve with increased fluid intake in Studies II-III. Probably this is due to methodological issues, that is the measurements used may not be sensitive enough. Nevertheless we think that a less strict fluid intake for patients with CHF will make life less difficult and more enjoyable.

There were some baseline differences between studies II and III. In Study II there were no significantly differences between the groups, whereas in Study III there were differences in age, weight and BMI between the groups. Patients in the group that had a lower fluid intake than 19 ml/kg/day were on average younger and heavier than in the group with a fluid intake at/above 19 ml/kg/day. Calculated based on the mean subject in the below median group, the average fluid intake was 1500 ml/day, whereas it was 1950 ml/day at/above median group. Based on the result that thirst was higher in the below median group, this may indicate that fluid intake is depending on body weight and therefore needs to be individualised.

As described in other studies, living with CHF affects daily life in many ways\textsuperscript{32-34}. In Study IV this is illuminated by the theme \textit{Hindering forces in daily life}. The physical limitations were the most evident, creating feelings of vulnerability and powerlessness. Lack of knowledge was not very prominent in Study IV, but when a low level of knowledge was present it had consequences for the patients. In some narratives it was obvious that the lack of knowledge had led to deterioration of the CHF with worsening symptoms and hospital admission as consequences. It is essential to
have good knowledge in order to perform self-care and it has been shown that both high levels of knowledge and beliefs influence the adherence to the pharmacological- and non-pharmacological treatment positively\textsuperscript{59, 60}. The rather good self-care behaviour in Study I and the fact that the patients in Study IV quite seldom described poor knowledge about CHF as a hindering force, shows that the development in CHF care has improved in Sweden, at least in research subjects.

The informants also expressed a willpower and optimism in their strive to create a good life for themselves and their relatives. This is described in the theme \textit{Facilitating forces in daily life} and it involves a process from understanding and accepting to adjusting. Similar processes are described by Mahoney\textsuperscript{104}, Stull et al.\textsuperscript{36} and Zambroski\textsuperscript{37}. In an educational and counselling situation it can be of importance to the nurse to recognise the phases in this process, in order to help the patient to adjust to the new life situation. This can be done in many ways. It is most important to listen to the patient and his/her every day issues or problems, and to use the patients own experiences to set achievable goals and support the personal, interpersonal and contextual conditions that can influence the outcome in a positive way\textsuperscript{105}. Another approach is to screen for risk patients using different kinds of instruments measuring, e.g. scales for depression- self-care behaviour- and knowledge. This could be helpful to the nurse in the effort to individualise the care, and it could make the care more effective in terms of time and costs.

\textbf{Methodological considerations}

Scientific methods incorporate all procedures that scientists have used, currently use, or may use in the future to pursue knowledge. Numerical data is used to describe, examine and to determine cause-and-effect interaction between variables. Analysis of narratives and words are used to describe, explain, and predict phenomena\textsuperscript{71}. In combination, these approaches can generate different kinds of knowledge on the same phenomenon and this is useful in nursing practise because of the holistic philosophy in nursing. The methodological strength in this thesis is that, both quantitative and qualitative data were used in describing and evaluating self-care behaviour and describing daily life experiences in patients with CHF, with special reference to fluid intake\textsuperscript{72}. However, all study design has its weaknesses and it is important to evaluate all threats to validity of the findings, as far as possible. To determine study validity, a critical analysis of the truth and accuracy in the research process is needed\textsuperscript{71}.
Quantitative data

Sub-study and secondary analysis design comprises the use of data gathered in a previous study, and the purpose can be to validate the reported findings, examine dimensions previously unexamined, or redirect the focus of the data. In this type of study it is very important to identify the source of the data so that the reader is not mislead to believe that the data is from a new study \textsuperscript{71}. Study I is a subgroup analysis of a larger randomised trial and the data used was derived from the intervention group of that trial. The reason for that was that, in Sweden today, many patients with CHF receive patient education and this trial provided the opportunity to describe the self-care behaviour regarding daily weighing and salt and fluid restriction under the circumstances of today. The question every scientist must ask is if the study generates new knowledge. In Study I most of the results confirm the results from other studies regarding self-care behaviour. However, since very little is known about daily weighing and salt and fluid restriction in particular, the results are of value. Another risk with sub-studies is the age of the data. The data in Study I was 6 years old when it was submitted to a journal. However, in term of treatment and management, there had not been any major changes in Sweden during those 6 years, so our judgement is that the results are valid also today.

Study III is a secondary analysis of Study II. The reason for that is that Study II is an intention-to-treat study, meaning that all subjects were analysed based on the randomised fluid recommendations, regardless of the reported, actual fluid intake, whereas the aim of Study III was to describe the self-reported fluid intake and its effects on the outcome variables. The results in studies II-III are very similar and support each other. This may be expected since the average reported fluid intake was almost the same in the 1.5L/day intervention and the \textless 19ml/kg/day group, as well as, in the 30ml/kg/day intervention and the \textgreater=19ml/kg/day group. It cannot be taken for granted that patients actually had the fluid intake they reported. However, the general opinion of the investigators is that the patients very accurately reported their fluid intake. The fluid protocol revealed that some patients did not adhere to the prescription in Study II, for example during the 1.5L/day intervention 8 patients drank more than 1600 ml/day and during the liberal intervention 5 patients drank less than 1400 ml/day. In order to objectively assess body fluid composition, several options for determining body composition were under consideration during the planning of the study, such as bioimpedance analysis and Dual-energy radiograph absorptiometry-based measurements (DEXA scan), but there was no financial support for this.
A cross-over design was used in Study II, i.e. the subjects participated in both interventions. There are several advantages and disadvantages with a cross-over design. One very important advantage is that the number of subjects can be decreased to half in comparison with ordinary randomised trials. Another advantage is that the subjects serve as their own controls and the intervention comparisons are within-subjects rather than between-subjects. The greatest disadvantage with the cross-over design is that there is a risk of carry-over effects, which means that the effects from the intervention in the first period affect the results of the second period. The randomisation procedure distributes any carry-over effects equally across all the conditions of the study and this reduces the risk that this effect might cause a false result. Another precaution that could be taken to minimize the risk of carry-over effects is to have a washout period. However, since very little is known about how long a washout period would have to be when the effects of fluid intake are examined, we decided to not have a washout period. Furthermore, a washout period requires a run-in period, and since all the subjects had been advised to adhere to a maximum daily fluid intake of 1.5L/day prior to study start, we believed that we had a sufficient run-in period, although the study did not have a formal run-in period. Run-in and washout periods extend the length of the study, which could have negative effects on recruitment of subjects. In Study II carry-over effects were found for thirst and difficulties to adhere to the fluid prescription measured by VAS-scale. Some statisticians recommend that a variable showing any carry-over effect should be excluded from the analysis, whereas others suggest that the results can be presented as we did in Study II if the carry-over effects are declared. A cross-over study needs to be twice as long as an ordinary two group study. Due to this there is a risk that the subjects become tired or bored with the study and decide to withdraw consent. This was not a problem in our study since only one subject withdrew consent and that was early in the study.

The choice of instruments is important in all scientific studies. EQ-5D is a standardised non-disease-specific survey instrument for describing self-perceived health status. This instrument is easy to understand and user friendly, which is important to consider when choosing instruments in trials including elderly and sick people. The EQ-5D has been criticized for sparse health state descriptions. Attempts has been made to redesign the questionnaire to overcome these problems, with satisfying results. It has also been criticized for poor sensitivity, particularly in disease-based outcome research, but it is widely used internationally and that is useful for comparisons of results between different diseases and conditions. In studies II-III, EQ-5D was combined with a disease-specific instrument, the MLWHF. Since none of these instruments address thirst, we searched for a domain-specific instrument on thirst. But
at the time of planning the study (study II-III) we could not find a suitable scale, so we decided to use VAS. This turned out well and the investigators’ perception was that the patients found it easy to use and understand. By this, the different types of scales were covered, i.e. generic, and disease- and domain-specific scales. The analyses were made on the total score and no calculations were made on the subscales of the instruments. Maybe the results had been different if analysis had been made on the subscales. On the other hand, the findings in health related quality of life may not be surprising, since no changes could be observed in symptoms, diuretic use or body weight. The quality of life instruments were not tested for internal consistency, because they are both widely used in research in patients with CHF.

The study population in studies II-III consisted of 74 subjects who were randomised to start with either of two interventions. This sample size was derived from a calculation based on the expected effect of the intervention on the self-perceived health status according to EQ VAS. Qualitative data

Four concepts, credibility, dependability, confirmability and transferability need to be addressed in order to achieve trustworthiness in research involving qualitative data. Credibility involves two aspects: first, how well the investigation is carried out and secondly, how well it is described. In Study IV the gender distribution was uneven among the informants, as opposed to the variation in age and time of illness. One reason for the uneven distribution in gender might be that men are more hospitalised for CHF than women. We conducted an analysis of the 206 patients admitted for CHF during one year at Malmö University Hospital, showing that two thirds were men.

The interviews were performed in a secluded office at the hospital. There is always a risk of interruptions in interview situations, like phone calls and visitors. To avoid such disturbing incidents, the phone was switched off and the door was locked. There is a possibility that the informants could have felt more secure and comfortable in their own home and, thereby, might have talked more freely about the daily life with CHF. However, the majority of the interviews were performed in connection with a scheduled visit to the out-patient clinic and the informants reported that they considered this very convenient. Also, most of the informants gave the impression of being open and honest. Two hours were allotted for the interviews and this was enough since no interview was longer than 60 minutes. Every interview was unique but the interviewer strived to perform the interviews in a similar way and in this respect the interview guide was helpful.
There is always a risk that the researchers’ pre-understanding may influence data collection, analysis and the interpretation of the text. The interviewer performing all interviews had previously worked as a nurse in a CHF unit. This, of course, has its advantages and disadvantages. One advantage is, in the interview situation, that the informants can feel secure, because of the interviewer’s knowledge about the problems the informant is facing and may, therefore, speak more freely. A disadvantage is that it is easy for the interviewer to direct the interview, consciously or unconsciously. However, the interviewer was well aware of this risk and tried to act as neutral as possible in the interview situation.

To ensure confirmability, i.e. that the data is objective and neutral, the analyses were performed separately by two authors (MH, ML) and in the latter part of the analysis the other two authors were involved to ensure dependability. Study IV was performed at a Swedish hospital with a well organised follow-up after hospital stay and this must be taken into account when transferring the results into other countries with other specific circumstances. The experiences of daily life for a person with CHF might also be transferable to persons with other chronic diseases.
FURTHER RESEARCH

Albert Einstein is supposed to have said; *Learn from yesterday, Live for today, Hope for tomorrow. The important thing is to not stop questioning.* In the work with this thesis it has became obvious that more knowledge is needed about the role of fluid intake in patients with CHF. The results in this thesis are only scratching the surface and there is much left to understand and to be done. More research must be done to clarify the pathophysiological aspects of the fluid balance in patients with CHF. Larger trials with more accurate measurements are needed to confirm the results from this thesis. Research is also needed concerning biological markers and the use of other objective measurements of body composition.

Patient education has been shown to improve self-care behaviour and adherence in patients with CHF, and nurse-led CHF clinics exist at almost all Swedish hospitals. As discussed in this thesis, the education and counselling needs to be individualised. For the clinical nurse, it can be a time consuming process to address all aspects of living with CHF. Development and testing of simple tools for self-care behaviour and strategies for use in clinical practise could be both time saving and cost effective. To meet the next generation of patients with heart failure, used to computers and internet and with higher demands on accessibility of information, other methods of follow-up needs to be developed. For example, instead of telephone hours chatting hours could be available. The possibility to send a question by e-mail or sms, and interactive web pages with information and counselling, are other issues for further development.
CLINICAL IMPLICATIONS

The results of this thesis indicate that it might be beneficial to individualise the fluid intake in patients with CHF. However, more research is needed before this can be established. For the nurses caring for patients with CHF this means a new challenge. Instead of a fixed fluid recommendation there is a need for a concordance in regard to fluid intake. In stable patients with CHF there may be no need for a fluid restriction, but if the patient displays clinical signs of volume overload one action that can be taken is restriction of fluid intake. In clinical practise this means that the patient education and follow-up needs to be more individualised. Nurses also need to screen for risk-patients and to evaluate how far the patient has developed in the process of becoming a patient with CHF. For some nurses this might be a new task and for this they need education in teaching. In order to help and support patients with CHF nurses have to go on increasing their knowledge about patients’ understanding and experiences of living with CHF.
CONCLUSIONS

The overall aim of this thesis was to describe and evaluate self-care behaviour and to describe daily life experiences in patients with CHF, with special reference to fluid intake.

- One single session of education is not enough to improve self-care behaviour and quality of life.

- A liberal fluid intake has favourable effects on thirst and adherence to the fluid prescription, without any detectable effects on physical capacity or morbidity in patients with stable CHF.

- A larger fluid intake was associated with decreasing thirst without any measurable negative effects on signs and symptoms of CHF, diuretic use, or physical capacity in patients with stable CHF.

- Living with CHF was experienced as forces that either hindered or facilitated the informants’ daily life. Hindering forces in life describes how limitations and difficulties affect daily life, whereas facilitating forces in life refers to how the informants manage and find balance in daily life.

The results of this thesis confirm the results from other studies regarding self-care behaviour and the experiences of living with CHF. This thesis reports on the first study evaluating the effects of an individualised fluid intake and, suggesting that a less restrictive fluid prescription may be safe and may facilitate daily life for patients with CHF. The findings of studies II and III need confirmation in larger studies.
POPULÄRVETENSKAPLIG SAMMANFATTNING

Egenvårdsbeteende och upplevelser i det dagliga livet hos patienter med kronisk hjärtsvikt.

Under min tid som kliniskt verksam sjuksköterska mötte jag många patienter som besvärades av törst och som hade svårt att följa den vätskerekommendation på 1,5L/dygn som gavs. Detta är upprinnelsen till denna avhandling vars syfte är att beskriva och utvärdera egenvårdsbeteendet samt att beskriva hur det dagliga livet upplevelser av patienter med kronisk hjärtsvikt, med speciellt intresse riktat mot vätskeintaget.

Kronisk hjärtsvikt är ett komplicerat kliniskt tillstånd som påverkar den drabbade individn på många sätt. Det finns ingen allmänt accepterad och heltäckande definition av kronisk hjärtsvikt. En vanligt förekommande beskrivning är att de tecken/symtom som kännetecknar hjärtsvikt indikerar att hjärtat av någon anledning inte kan förse kroppens vävnader och organ med den mängd syre och näring som behövs. Gemensamt för alla definitioner av kronisk hjärtsvikt är att den orsakas av en bakomliggande hjärtsjukdom. De vanligaste orsakerna till kronisk hjärtsvikt i Europa är högt blodtryck och hjärtkärlssjukdom, ofta i form av genomgången hjärtinfarkt. Andra orsaker kan vara rytmrubningar i hjärtat, klaffsjukdom eller hjärtmuskelsjukdom. Cirka två till tre procent av befolkningen i Sverige (200 000-250 000 individer) har kronisk hjärtsvikt och det uppskattas att andelen personer som har en asymtomatisk eller latent hjärtsvikt är lika stor. Det stora flertalet av dessa personer är äldre; cirka 10 procent av befolkningen över 80 år har kronisk hjärtsvikt. Förekomsten av kronisk hjärtsvikt har ökat under de senaste decennierna och anledningen anses vara att medellivslängden har ökat och behandlingen av akut hjärtinfarkt har förbättrats avsevärt, med förbättrad överlevnad som följd, men också till priset av att fler människor lever


Förutom de vanliga symtomen är törst något som patienter med kronisk hjärtsvikt ofta uttrycker som besvär. Orsaken till detta kan vara flera; den vätskedrivande behandlingen är en, den stresshormonella aktivering en annan och den vätskerestrisktion som patienterna är rekommenderade kan vara den tredje. I gällande riktlinjer rekommenderas en vätskerestrisktion på 1,5-2 l vätska per dygn men denna rekommendation bygger inte på någon vetenskaplig kunskap. Förutom törst är munttorrhet ett problem som i sin tur kan leda till förändrat smaksinne, försämrad munhälsa och i värsta fall svårigheter att tala. Torr hud och klädorna är också symtom som kan kopplas samman med en strikt vätskerestrisktion. Kroppens behov av vätska anges i litteraturen vara mellan 25 och 35 ml/kg kroppsvikt/dygn. Räknat på 30 ml/kg kroppsvikt/dygn skulle 1,5 l täcka behovet för en person som väger 50 kg och för en person som väger 80 skulle gällande riktlinjer innebära ett dagligt underskott på nästan 1 liter. När den farmakologiska behandlingen för kronisk hjärtsvikt inte var så utvecklad som den är idag var vätskerestrisktion en naturlig och motiverad åtgärd, men med dagens effektiva farmakologiska behandling bör behovet av denna vätskerestrisktion omprövas efter som den medför obehag för patienterna.

Syftet med denna avhandling var att beskriva och utvärdera egenvårdsbeteendet samt att beskriva hur det dagliga livet upplevs av patienter med kronisk hjärtsvikt, med speciellt intresse riktet mot vätskeintaget. Syftet med delstudie I var att beskriva egenvårdsbeteendet hos patienter med kronisk hjärtsvikt inom primärvården under ett år efter en patientutbildning. Studien var en analys gjord på interventionsgruppen i en större randomiserad studie. Interventionen bestod av ett utbildningstillfälle i hemmet genomförd av en sjuksköterska från primärvården. Uppföljningen skedde sedan via telefon varje månad under ett år, förutom månad tre och tolv då uppföljningen skedde i hemmet. Sextio patienter utvärderades och resultaten visade ingen förändring i egenvårdsbeteende, avseende viktkontroller, salt- och vätskerestrisktion under uppföljningstiden. Inget samband sågs mellan hälsorelaterad livskvalitet och egenvårdsbete-
ende. Det fanns inga könsskillnader i egenvårdsbeteende eller i sambandet mellan hälsorelaterad livskvalitet och egenvårdsbeteende. Resultaten indikerar att det inte räcker med ett utbildningstillfälle för att förbättra egenvårdsbeteendet och den hälsorelaterade livskvaliteten.

Delstudie II var en randomiserad cross-over studie, vilket innebär att alla patienter deltar i båda de interventioner som studien omfattar. Varje patient blir därmed sin egen kontroll. Under intervention 1 fick patienterna inte dricka mer än 1,5L/dag och under intervention 2 baserades rekommendationen om det maximala vätskeintaget på kroppsvikten; 30ml vättska per kg kroppsvidk/dygn. Sjuttonfyrat patienter randomiserades och syftet var att utvärdera effekterna av vätskeintaget på hälsorelaterad livskvalitet, fysisk kapacitet, törst och sjukhusinläggning hos patienter med stabil kronisk hjärtsvikt. Resultatet visade ingen skillnad mellan interventionerna avseende hälsorelaterad livskvalitet, fysisk kapacitet eller inläggning på sjukhus. Upplevelse törst och svårigheter att hålla vätskerekommendationen var dock signifikant mindre i gruppen som hade en individuellt anpassad vätskerekommendation. Resultatet antyder att en mindre strikt vätskerekommendation är både säker och fördelaktig för patienter med stabil kronisk hjärtsvikt, vilket aldrig tidigare visats.

Delstudie III bestod i en sekundäranalys av data från delstudie II. Syftet var att beskriva patienternas uppgivna vätskeintag samt dess effekter på kroppsvikt, symtom, diuretikaanvändande, hälsorelaterad livskvalitet och fysisk kapacitet. Data från 63 patienter ingick i analysen. Gruppindelningen baserades på medianen (19ml/kg kroppsvidk/dygn) av intagen vättska för hela studieperioden. Medelvärdet av intagen vätska i ”under median gruppen” var 16 ml/kg kroppsvidk/dygn, medan det var 24 ml/kg kroppsvidk/dygn i ”över median gruppen”. Inga skillnader mellan grupperna sågs förutom en signifikant mindre upplevelse av törst och svårigheter att hålla vätskerestriktionen i ”över median gruppen”. Resultatet antyder, som i delstudie II, att en mindre strikt vätskerekommendation inte har några negativa effekter på hälsan hos patienter med stabil kronisk hjärtsvikt, medan patientens törst kan minsas.

Delstudie IV var en intervjustudie som analyserades med manifest och latent innehållsanalys. Femton personer intervjuades och syftet var att beskriva hur personer med kronisk hjärtsvikt upplever och hanterar sitt dagliga liv. Resultatet beskrivs i två huvudteman Hindrande och Främjande krafter, där hindrande krafter belyser fysiska och psykiska svårigheter i det dagliga livet medan främjande krafter beskriver hur personer med kronisk hjärtsvikt accepterar, anpassar sig och hanterar sitt dagliga liv.
Sammanfattningsvis visar denna avhandling att hjärtsvikt påverkar den hälsorelaterade livskvaliteten och det dagliga livet både fysiskt och psykiskt (Studie I, IV). Följ- 
samheten till den egenvård som rekommenderas är relativt god men ska den förbättras 
ytterligare krävs mer än ett utbildningstillfälle (Studie I). Den törst som många patien-
ter med hjärtsvikt upplever som besvärande (Studie II-IV) kan utan märkbara negati-
va effekter minskas genom att rekommendera en mindre strikt vätskerekommendation 
(Studie II, III). Därmed kan en begränsning i livet tas bort och det dagliga livet bli lite 
lättare att leva för patienter med hjärtsvikt (Studie IV).
ACKNOWLEDGEMENTS

This thesis was carried out at the Faculty of Health and Society, Malmö University, Sweden and at the Department of Cardiology, Malmö University Hospital MAS, Sweden. I am ever so grateful for the opportunity and privilege to perform this doctoral education. From the depth of my heart I would like to thank everyone how had supported and encouraged me throughout this work. It has made me feel special and with that feeling you can move mountains. I would sincerely like to thank;

The persons participating in the studies, for their patience throughout the follow-up period and for sharing their life experiences with me.

My head-tutor Ass. Professor Ronnie Willenheimer whom with honesty and delicacy has guided me into the research world. I cherish great admiration for your knowledge and dedication in science. Thank you for always being so optimistic and wise and telling me things like Only the sky is the limit with such conviction that I actually believe in it.

My co-tutor Ass Professor Anna Strömberg. From the very first time I met you, you has served as a role model to me. Clever, competent and sensible are only some of the distinctive features you have. I am truly grateful for the advise, support and knowledge you have given me throughout the years.

My co-tutor PhD Maud Lindholm. For your engagement and encouragement which have helped me to go forward. Your enthusiasm for and knowledge in qualitative research has truly influenced me. With wisdom and patience you have introduced me to the academic world.
My former tutor Prof. Emeritas Giggi Udén and former Head of Caring at the Department of Cardiology Gunilla Edberg for making it all possible. Thank you for the trust and for believing in me.

PhD Ole Hansen and PhD Bo Israelsson, present and former head of the Department of Cardiology, and former head of caring Ulla Blomé for support and the possibility to carry out the studies at the department.

PhD Ulla Edell-Gustafsson Lecture at Linköping University and PhD Martin Stagmo at the Department of Cardiology, Malmö University Hospital for valuable input at “half-time” and to PhD Evy Lidell, Lecture at Halmstad University, for a very fruitful discussion at my pro-dissertation. PhD Helena Jernström, Lecture at the Faculty of Health and Society, Malmö University for making the statistics comprehensive to me.

My friends and colleagues at the Faculty of Health and Society. Past and present PhD students for interesting and sometimes very funny discussions about life as a PhD student. The senior lecturers and PhD students in the seminar group for instructive discussions and invaluable feedback of my work. My fellow teachers in “the clinical teacher project”, in particular Anna-Karin Wahn and Mari Åberg.

All my friends and colleagues at the Department of Cardiology for showing such an interest in my work. Especially I would like to thank my two friends Alicja Arsimowicz and Janeth Feldtblad whom not only have assisted me in the work with this thesis but also have been there for me in the ups and downs in life.

And last but not least all my beloved family who have supported and encouraged me throughout my doctoral education. First of all my parents, Maj and Ingvar, for being the persons I always could count on for support and unconditional love. My brothers, Nils-Erik and Per, for all the help you have given me during the last years. Ulrika, for interesting and instructive discussions about science during family dinners. My children, Erika, Anna and Beatrice, I can not find words strong enough to express my love for you but you should know that it is everlasting and solid as a rock. My fiancé Lennart for all the joy and love you bring in to my life.
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