Family caregiving
for persons with heart failure
Perspectives of family caregivers,
persons with heart failure and registered nurses

Annelie K Gusdal
In loving memory of my Mother

När paraden har tystnat i fjärran
och klockor och sånger vikt av
flylls salen upp med kristaller
som du lämnade kvar

När allt man försöker att säga
finns i en tyst minut
världen är full av kristaller
och aldrig mer som förut

‘Kristaller’ by Laleh, 2016
ABSTRACT

**Background:** Heart failure is a growing public health problem associated with poor health-related quality of life and significant morbidity and mortality. Family support positively affects self-management and outcomes for the person with heart failure while also leading to family caregivers’ significant caregiver burden and reduced health-related quality of life. Registered nurses frequently meet family caregivers to a person with heart failure in various health care settings and have a key role in meeting the needs of family caregivers. In view of the central role families play in heart failure care and self-management to improve health outcomes it seems essential to prepare registered nurses for the challenges and opportunities of sufficiently supporting families living in the midst of severe chronic illness.

**Aim:** The overall aim of this thesis was to explore the situation and needs of family caregivers to a person with heart failure, and to explore the requisites and ways of supporting and involving family caregivers in heart failure nursing care.

**Methods:** The thesis is based on two qualitative interview studies (I+II), one quantitative web-survey study (III) and one intervention study (IV) conducted between 2012 and 2017. A total of 22 family caregivers, eight persons with heart failure and 331 registered nurses were included in the studies. The interviews and the intervention took place in three hospitals and three primary health care centres in one county. The web-survey included 47 hospitals and 30 primary health care centres in various parts of Sweden.

**Results:** Family caregivers’ daily life was characterized by worry, uncertainty and relational incongruence but salutogenic behaviours restored their strength and motivation to care. Family caregivers experienced that health care professionals took family caregiving for granted without supplying the family caregivers with support and appropriate tools to facilitate their situation. Neither were family caregivers invited to share information with health care professionals nor was their specific expertise requested. This gave rise to feelings of exclusion and had a negative influence on family caregivers’ relationship with their near one. Family caregivers expressed a need for a permanent health care contact and more involvement with health care professionals in the planning and
implementation of their near one’s health care (I). Registered nurses acknowledged family caregivers’ burden, their lack of knowledge and relational incongruence. However, registered nurses neither acknowledged family caregivers as a resource nor their need for involvement with health professionals. A registered nurse, as a permanent health care contact, was suggested to improve family caregivers’ continuity and security in health care (II). Previous research has found that registered nurses’ supportive attitudes towards families are requisites for involving families in nursing care. This thesis found that registered nurses who worked in primary health care centres, in nurse-led heart failure clinics, with district nurse specializations, with education in cardiac and/or heart failure nursing care were predicted to have the most supportive attitudes towards family involvement in heart failure nursing care (III). Family Health Conversations via telephone in nurse-led heart failure clinics were found to successfully support and involve families in heart failure nursing care. The conversations enhanced the nurse-family relationship and relationships within the family. They also provided registered nurses with new, relevant knowledge and understanding about the family as a whole. Family Health Conversations via telephone were feasible for both families and registered nurses, although fewer and shorter conversations were preferred by registered nurses (IV).

Conclusions: This thesis highlights the divergence between family caregivers’ experiences and needs, and registered nurses’ perceptions about family caregivers’ situation and attitudes towards the importance of family involvement. It adds to the knowledge on the importance of registered nurses to acknowledge family caregivers as a resource, and to support and involve them in heart failure nursing care. One feasible and successful way to support and involve families is to conduct Family Health Conversations via telephone in nurse-led heart failure clinics. Keywords: Attitudes, cardiovascular nursing, caregiving, content analysis, family, family caregiver, family health conversation, family-centred nursing, family systems theory, heart failure, informal caregiver, interview, intervention, involvement, older person, pretest-posttest design, questionnaire, support, telephone, web-survey.
LIST OF SCIENTIFIC PAPERS

This thesis is built on the following four papers, which are based on four studies, and referred to by their Roman numerals.


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## LIST OF ACRONYMS

<table>
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<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ESC</td>
<td>European Society of Cardiology</td>
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<td>FamHC</td>
<td>Family Health Conversation</td>
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<td>FC</td>
<td>Family Caregiver</td>
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<td>FGI</td>
<td>Focus Group Interview</td>
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<td>FSN</td>
<td>Family Systems Nursing</td>
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<td>HF</td>
<td>Heart Failure</td>
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<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
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<td>IBM</td>
<td>Illness Belief Model</td>
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<td>PHCC</td>
<td>Primary Health Care Centre</td>
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<td>RN</td>
<td>Registered Nurse</td>
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“You don’t have to believe everything you think”

Eckhart Tolle
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1 INTRODUCTION

1.1 My personal point of departure

This PhD thesis aims to acknowledge the importance of the family in heart failure nursing care and to find ways of supporting and involving families affected by heart failure. Long-term illness not only affects the person with the illness but the entire family and their daily lives. Each family has to adjust to its new situation and needs to find solutions to various new challenges. In contacts with health care, families frequently experience lack of support and perceive themselves as invisible to the health care professionals. When reflecting on my own professional background as a registered nurse and district nurse, in both hospital care and basal home health care, I now understand that I almost solely focused on the persons who were ill. I appreciated the caregiving and dedication of the surrounding spouses, children, neighbours, colleagues and friends but I did not reflect on their eventual caregiver burden or on needs they might have had. Whereas they did not explicitly express any discomfort or illness I was pleased to continue focusing on my busy tasks. As I have now found in my research, my previous focus on only the person with the illness is one shared with many fellow colleagues.

Professionally, I first became aware of family caregivers’ situation and needs when working with palliative care in advanced home health care. I worked primarily with persons who had cancer but also with persons who had advanced heart failure. I then understood another way of interacting with family caregivers. In advanced home health care, it was self-evident to involve the family caregivers in the everyday care of the ill persons and it was equally important to build a relationship with the family caregivers as with the person who was ill. When discussing and planning care in the multidisciplinary health care team, time and attention were equally devoted to the person who was ill and their family caregiver, the family unit. The families’ satisfaction and trust in the advanced home health care team far compensated for the eventual extra effort we put in.
The original aim of my research project was to identify and develop methods for early identification of those persons at risk of becoming the ‘most ill older persons’. Although this is an important research area, I found my research area of interest when updating myself on the admittance registrars of the county hospital in Västerås. I learned that persons 65 years and older with heart failure constituted the majority of those who were admitted, and readmitted within three months, to hospital care. I also learned that their family caregivers were often responsible for the decision to seek hospital care. As the illness trajectory in heart failure is a particularly difficult one, one can assume that family caregivers experience a substantial caregiver burden, which deserves acknowledgement.

While my research project progressed, I gradually became aware that I had been myself a family caregiver to my now late mother with heart failure for 16 years. Similar to other family caregivers, I neither defined myself as a caregiver, nor was I comfortable with the concept. I was a daughter who out of loving companionship and duty helped and comforted my mother to the best of my ability. Thus, I did not expect or demand any support or concern from health care for my own part. From both a professional research perspective and a personal perspective, I have now witnessed how family caregivers constitute a ‘quiet’ and marginalized group within the health care system. There appears to be a blind spot affecting both family caregivers and health care professionals on the need to duly acknowledge and support the family caregivers, and the family as a unit, in both their burden and in their accomplishment. As the ill health of persons with heart failure and their family caregivers will grow, and as the prevalence of heart failure increases, action for change is due in which support and the involvement of family caregivers is genuinely addressed in health care.

My target groups for this thesis are family caregivers to a person with heart failure, and registered nurses in hospitals, primary health care centres and in home health care. In these health care units registered nurses meet persons with heart failure and their family caregivers on a daily basis, and here a more family-centred approach is highly commendable.

1.2 A health and welfare perspective
Over the past 30-35 years, the incidence and mortality in cardiac disease, including heart failure (HF), has steadily declined in Sweden (SoS, 2009,
During the 1980s, there were major breakthroughs in the treatment of HF. Enhanced pharmacological and invasive therapies have improved prognosis in HF but have also increased the number of persons living with HF. The reduced fatality rate after acute coronary syndromes in the last decade, in combination with population ageing, further contribute to an increased prevalence of HF (Ponikowski et al., 2016; Yancy et al., 2013). HF has become a growing public health problem and persons with HF constitute, in part, the ‘most ill older persons’ with comprehensive health care, social care and home care needs in Sweden (SKL, 2011; SoS, 2011).

Increasing age, illness and the need for health care and social care run parallel and the growing number of older persons in Sweden has not been met with a corresponding increase in health care and social care; rather the opposite (Szebehely & Ulmanen, 2008). Since the 1980s, publicly financed eldercare services in Sweden have declined. During the 2000s, the number of beds in residential care was reduced by 25% and the increase in homecare services did not compensate for the decline (Szebehely & Ulmanen, 2012). With a decline in health care and social services, the Swedish welfare state has moved away from its original ideals of universalism, which has resulted in a re-familiarization process (SKL, 2014; Ulmanen, 2015). This development in the society, along with the official policy that older persons should continue to live in their ordinary homes as long as possible, has led to a shift from public, formal care to family caregiving; thus increasing ill and older persons’ dependency upon their families to meet their care needs (Szebehely & Ulmanen, 2012).

In Sweden, more than 1.3 million persons provide support and care for a near one; of these, at least 900 000 are of working age. Approximately 75% of the total support and care for ill and older persons living in their ordinary home is to some extent provided by family caregivers (FCs) (SoS, 2012). Similarly, the majority of support and care for older persons with HF is provided by FCs (Pressler et al., 2013). The decline in publicly financed services has reduced the extent to which family caregiving is voluntary. There are no juridical requirements that family members must provide care and support to their near ones, besides parents under the Parental Code (SFS 1949:381) who are obliged to care for their children until they turn 18, and spouses under the Marriage Code (SFS 1987:230) who must help each other with chores and financial expenses. Instead, it is still the society’s responsibility to provide support and care in the form of various health care and social services. Nevertheless, the majority of care is family caregiving,
which thus constitutes a societal support function and is not only a supplement to health care and social services (SoS, 2014b). In 2009, the legislation supporting FCs was strengthened in §10 Ch.5 of the Swedish Social Service Act (SFS 2001:453), which states that the Social Welfare Board in each municipality is obliged to provide support to persons who give care to near ones who are long-term sick or older. The National Board of Health and Welfare (SoS, 2013) and the Swedish National Audit Office (Riksrevisionen, 2014) monitored the Social Service Act (SFS 2001:453) between 2010-2013 and concluded that the municipalities’ support lacked both quality and flexibility. In the Health Care Act (SFS 1982:763) that regulates health care, the provision of support to adult FCs is not stipulated at all.

Help, support and care are commonly seen as a natural foundation of a relationship we have with our near ones, and sometimes caregiving causes no major problems in FCs’ daily lives. However, difficulties of various kinds occur, such as physical, cognitive and emotional fatigue and exhaustion besides feelings of social isolation and lack of support (Sand, 2014). Furthermore, there may also be negative consequences for FCs’ employment, and if caregiving becomes very demanding it may be necessary to reduce working hours or stop working completely to provide care (Sand 2014; SoS, 2012). Given the consequences of family caregiving, health care and social services therefore must consider FCs’ situation at an early stage and actively offer support and assistance, in order to secure the health and welfare for the FCs of today and in the future.
2 BACKGROUND

2.1 Heart failure

2.1.1 Symptoms, signs, diagnosis and aetiology

HF is a clinical syndrome characterized by an insidious deterioration of the typical symptoms of dyspnoea, ankle oedema and fatigue that may be accompanied by signs of elevated jugular venous pressure, pulmonary crackles and displaced apex beat. HF is associated with several other symptoms including weakness, diffuse pain, loss of appetite, anxiety, depression and sleep disorders (Alpert, Smith, Hummel, & Hummel, 2017; Patel, Shafazand, Schaufelberger, & Ekman, 2007; Ponikowski et al., 2016). HF leads to various levels of symptom and functional severity that can be graded into four levels, or NYHA classes, according to the Criteria Committee of the New York Heart Association (1994). The NYHA classification system considers the person’s symptoms in relation to daily activities. It is a valid and simple measure of functional status used in clinical practice (Bennett, Riegel, Bittner, & Nichols, 2002). Acute HF refers to a rapid onset or worsening of symptoms and/or signs of HF. It is a life-threatening medical condition requiring urgent evaluation and treatment, typically leading to acute hospital admission (Ponikowski et al., 2016).

HF is largely a clinical diagnosis based on a careful history and physical examination (Yancy et al., 2013). The diagnosis relies on data obtained from self-report, medical records and physical examination. In addition, data from testing such as natriuretic peptides, electro-cardiogram, echo-cardiography and cardiac magnetic resonance is incorporated (Dunlay & Roger, 2014; Ponikowski et al., 2016). Demonstration of an underlying cardiac cause is central to the diagnosis of HF. The aetiology of HF is not yet fully known but hypertension, diabetes, coronary artery disease, obesity and a history of smoking are the most notable factors that predispose a person to HF (Ponikowski et al., 2016).
2.1.2 Epidemiology and prognosis

Approximately 26 million persons live with HF worldwide (Ambrosy et al., 2014). Braunwald (2015) states the estimated prevalence is as high as 38 million persons. HF is rapidly growing, primarily due to the growing number of older persons in the population (Roger, 2013). Improved management and survival after acute coronary syndrome also contribute to an increased prevalence of HF (Dunlay & Roger, 2014). The estimated prevalence of HF in Sweden is 2.2% of the adult population, rising to ≥10% among persons >70 years (Zarrinkoub et al., 2013). Among persons 65 years and older presenting to primary care with breathlessness on exertion, one in six will have unrecognized HF, mainly with preserved ejection fraction (van Riet et al., 2014). The average age of persons with HF is 75 years. Men are diagnosed earlier than women (mean age 70 versus 76 years), as men have acute coronary syndrome earlier; men also have a worse prognosis for survival than women do (Dunlay & Roger, 2014; Zarrinkoub et al., 2013).

Over the last 30 years, improvements in treatments and their implementation have improved survival and reduced the hospitalization rate in persons with HF. Mortality from HF has also steadily declined in recent decades, largely reflecting the introduction of medications, such as angiotensin-converting enzyme inhibitors (ACEI), or angiotensin receptor blocker (ARB), and beta-blockers (Dunlay & Roger, 2014; Ponikowski et al., 2016). However, despite these improvements, HF remains associated with poor outcomes. After initial diagnosis of HF, the estimated survival is 72-75% at one year and 35-52% at five years (Barasa et al., 2014; Levy et al., 2002; Roger et al., 2004; Yeung et al., 2012).

2.1.3 Treatment, multimorbidity and health care utilization

The primary goals of HF treatment are to relieve symptoms, prevent hospital admissions and extend survival. Pharmacological treatment with diuretics, ACEI or ARB, beta-blockers and mineralocorticoid receptor antagonist are first-line medications and recommended for the treatment of every person with HF (Ponikowski et al., 2016). Furthermore, cardiac resynchronization therapy and implantable cardioverter-defibrillators have improved prognosis in HF but have also increased the number of persons living with advanced HF (SoS, 2015a, 2015b; Yancy et al., 2013).
Multimorbidity in HF is a growing concern in older persons who may experience multiple symptoms of several conditions coupled with progressive vulnerability and frailty (Benjamin et al., 2017; Ponikowski et al., 2016). Chronic obstructive pulmonary disease and atrial fibrillation commonly complicate the management of HF, especially when accompanied by physical deficits and concurrent psychosocial issues (Stewart, Riegel, & Thompson, 2016). Clinical guidelines suggest that multimorbidity is a distinct clinical entity and a goal-oriented approach should be applied to improve outcomes (Tinetti, Fried, & Boyd, 2012).

HF is the single most frequent cause of hospitalization in persons ≥65 years (Roger, 2013; SoS, 2015a, 2015b). Up to 25% of persons hospitalized with HF are readmitted within 30 days (Dharmarajan et al., 2013). A total of 75% of the costs of HF are related to acute hospitalizations. Worsening of symptoms of HF, in particular dyspnoea, is the primary reason for readmission but multimorbidity, non-adherence and non-optimal treatment are important contributing factors (Annema, Luttik, & Jaarsma, 2009; Patel et al., 2007; Strömberg, 2006). Guidelines from the European Society of Cardiology (ESC) (Ponikowski et al., 2016) and the Swedish National Board of Health and Welfare (SoS, 2015a, 2015b) emphasize the importance of a multifaceted strategy for HF care. The strategy consists of receiving an optimized diagnosis, adequate pharmacological and surgical treatment, lifestyle counselling, discharge planning, multidisciplinary professional help and improved coordination of HF care between primary and secondary care.

2.1.4 Nursing management and interventions

The goal of nursing management of HF is to provide a ‘seamless’ system of care that embraces both primary and secondary care (Ponikowski et al., 2016). Multidisciplinary management programs are fundamental and should be designed to improve outcomes through structured follow-up with self-care education, psychosocial support, optimization of medical treatments and improved access to care (Sochalski et al., 2009). Nursing management of persons with HF varies according to the site and geographical location in which the registered nurse (RN) is working. The role of the RN is broad and can involve home visits, telephone contact, facilitating tele-monitoring, running nurse-led HF clinics, as well as providing education for health professionals involved in the management of the persons with HF. The two main areas of nursing management are education and monitoring of the
person’s health status, symptoms and Health-Related Quality of Life (HRQoL) (McDonagh et al., 2011). Areas to cover in the educational package are information on indications of deterioration in the condition of the person with HF and on self-monitoring activities, such as titration of diuretics and daily monitoring of weight (McDonagh et al., 2011; Ponikowski et al., 2016).

Nurse-led HF clinics have been in operation in Sweden since 1990 with the purpose of following up persons with HF after discharge from hospital. During the 2000s, nurse-led HF clinics started up in two-thirds of the Swedish hospitals (Strömberg, Mårtensson, Fridlund, & Dahlström, 2001). Follow-up after hospitalization at a nurse-led HF clinic can reduce mortality, the number of readmissions and days in hospital (Roccaforte, Demers, Baldasarre, Teo, & Yusuf, 2005; Takeda et al., 2012). Both Swedish and international ESC guidelines advocate the implementation of nurse-led HF programs to achieve optimal management of HF (Ponikowski et al., 2016; SoS, 2015a, 2015b; Yancy et al., 2013). Today, nurse-led HF clinics are widely deployed in hospitals but only to a limited extent in primary health care, although more than 50% of the continuous care and treatment of persons with HF takes place there (Strömberg, 2006). Mårtensson and colleagues (2009) found that only 18% of Sweden’s Primary Health Care Centres (PHCCs) had nurse-led HF clinics. This compares with nurse-led diabetes clinics and nurse-led asthma and chronic obstructive pulmonary disease clinics that are available in 93% and 78% of Sweden’s PHCCs, respectively. Reasons for the low deployment may be that the true incidence of HF is underestimated (Hobbs, Jones, Allan, Wilson, & Tobias, 2000), but also after proper estimation of the incidence of HF, it may be too low to justify nurse-led clinics (Mårtensson et al., 2009).

The challenge today is to find an optimal cost-effective care model for the growing number of persons with HF. Creative models are needed, such as home-based or hybrid primary health care-based and hospital-based programs. The ‘classic’ HF clinic still has its place but with new components such as tele-monitoring or tele-education (Jaarsma & Strömberg, 2014). Inglis, Clark, Dierckx, Prieto-Merino and Cleland (2017) found in their review that structured telephone support offer statistically and clinically meaningful benefits to persons with HF; the primary outcomes including all-cause mortality and all-cause and HF related hospitalisations. Primary health care could also have programs in which RNs work with more than one
illness, for example both persons with HF and persons with coronary artery disease (Khunti et al., 2007).

Currently, most HF nursing interventions primarily focus on the person with HF to improve outpatient self-care (Lum, Lo, Hooker, & Bekelman, 2014), while guidelines for the management of HF recommend involving family members in education, in the provision of psychosocial support, and in the planning of care at discharge (Ponikowski et al., 2016; Yancy et al., 2013). Research also emphasizes the central role that RNs have in providing psychosocial support and meeting the needs of FCs to a person with HF (Jaarsma & Strömberg, 2014; Ågren, Evangelista, Hjelm, & Strömberg, 2012). In a recent review, summarizing research interventions directed towards FCs for a person with HF, 16 interventions were found (Dionne-Odom et al., 2017). These interventions varied considerably in aim, sample sizes, outcomes assessed and methodological rigour. Of these were 10 randomized controlled studies, of which three reported a statistically significant reduction in caregiver burden and depressive symptoms for FCs: two of the studies used telephone support (Piamjariyakul et al., 2015; Piette, Striplin, Marinec, Chen, & Aikens, 2015) and one was an educative group intervention (Etemadifar, Bahrami, Shahriari, & Farsan, 2014). The remaining six interventions were of a quasi-experimental and non-randomized design, of which three reported improvements for FCs: two studies used telephone support, which showed reduced caregiver burden and improved stress management and family function (Chiang, Chen, Dai, & Ho, 2012), reduced caregiver burden (Piamjariyakul, Smith, Russell, Werkowitch, & Elyachar, 2013), and one used psychoeducational and skill-building small group sessions that showed improvement in relationship quality and health for FCs (Sebern & Woda, 2012). Of the above six successful interventions, four involved both the persons with HF and FCs, while two focused solely on the FCs.

Dionne-Odom and colleagues (2017) recommend to further target family communication skills and relational congruence. These recommendations are in line with other researchers (Lum et al., 2014; Sebern & Woda, 2012; Hartmann, Bázner, Wild, Eisler, Herzog, 2010) who emphasize that future HF nursing interventions should recognize the importance of family relationships and an improved understanding of family relationship quality. Chesla (2010) found in her review that family interventions with a relationship focus showed a reduction in depressive symptoms, anxiety levels and family burden within the family.
A small but growing body of family intervention studies in the area of Family Systems Nursing (FSN) and the Swedish family-centred nursing (see section 2.3) shows promising results (Östlund & Persson, 2014). Evidence is accumulating on the positive outcomes on RNs’ conceptual skills, job satisfaction and on strengthening the nurse-family relationship (Dorell, Östlund, & Sundin, 2016; Duhamel, Dupuis, Reidy, & Nadon, 2007). Family interventions have also been shown to be a healing experience; to improve family relationships, alleviate suffering and to be psychologically empowering for families (Benzein, Olin, & Persson, 2015; Benzein & Saveman, 2008; Dorell, Bäckström et al., 2016; Dorell, Isaksson, Östlund, & Sundin, 2016; Dorell & Sundin, 2016; Duhamel et al., 2007; Duhamel & Talbot, 2004; Martinez, D’Artois, & Rennick, 2007; Sundin et al., 2016; Svavarsdottir, Tryggvadottir, & Sigurdardottir, 2012; Voltelen, Konradsen, & Østergaard, 2016; Östlund, Bäckström, Saveman, Lindh, & Sundin, 2016). To date, there have been few FSN/family-centred nursing interventions in HF nursing care (Duhamel & Talbot, 2004; Duhamel et al., 2007; Voltelen et al., 2016) and the empirical research evidence on family nursing interventions in HF nursing care needs to be considerably expanded and strengthened.

2.2 Living with heart failure

A person with HF is henceforth also referred to as a near one or family member. In paper I, an FC was referred to as informal caregiver. As the research project progressed further into the area of FSN (see section 2.3) the term changed from ‘informal caregiver’ to FC in papers II-IV. An FC is also referred to as a family member. When the FC and the person with HF are spoken of as a unit, they are referred to as ‘family’.

2.2.1 Older persons with heart failure

HF is prevalent in all age groups, whereas the attention in this thesis is placed on the HF nursing care and family caregiving for persons ≥65 years. While increased use of echo-cardiography has led to better understanding of the prevalence of diastolic dysfunction, or preserved systolic function, in older persons, HF is still frequently undiagnosed in this age group due to non-specific symptom presentations and multimorbidity (Benjamin et al., 2017). Compared with younger age groups, older persons have more difficulty in detecting and interpreting symptoms of dyspnoea, and are more likely to report a different level of dyspnoea than that noted by the health
care professionals (Riegel et al., 2010). Several problems associated with communication between older persons with HF and their health care professionals prevail, especially in relation to the complex terminology associated with the condition and its prognosis. Most persons have limited knowledge about HF, with the majority believing that the condition is a result of their old age, which undermines the importance of regular symptom monitoring that enables early detection and treatment of HF exacerbations (Barnes et al., 2006).

Physical symptoms, such as dyspnoea and fatigue, and depression, social isolation and existential concerns can prevent persons with HF from performing their daily activities (Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008; Cortis & Williams, 2007). Fatigue intensity can be associated with dissatisfaction with life and perceived strain in activities of daily life. The experience of fatigue can be characterized as a loss of physical energy leading to discrepancy between intention and capacity (Hägglund, Boman, & Lundman, 2008). In older persons with fatigue, Ekman and Ehrenberg (2002) found that more women than men expressed limitations in performing socially defined roles in the context of home and family, leading to dependency in everyday activities. The majority of older persons with HF depend on others in tasks essential to household management, such as meal preparation, shopping and managing money (Norberg, Boman, & Löfgren, 2008, 2010). The transition to dependency is often combined with a fear of being a burden to others. Persons with HF have been found to not want to talk about, or acknowledge, the severity of their illness and the gradual decline in their functional status (Gott, Small, Barnes, Payne, & Seamark, 2008; Waterworth & Gott, 2010). For persons with HF, the HRQoL is often poorer than for persons with other chronic illnesses. Poorer HRQoL is predicted by being female, of older age, in NYHA functional class III or IV, showing evidence of depression, and experiencing multimorbidity (Gott et al., 2006; Heo et al., 2013). Gallagher and colleagues (2016) found that persons with a high level of social support reported fewer negative effects of HF on HRQoL. Besides positive effects on HRQoL, social support also positively affects self-care maintenance (Salyer, Schubert, & Chiaranai, 2012; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008); thus improving adherence to medication treatment and reducing severe symptoms.
2.2.2 Family caregivers to older persons with heart failure

Often there are friends, family, neighbours and co-workers at a distance or close by who help, support and care for a person who falls ill. As a person with HF is influenced by their condition, it can be assumed that so are the persons in the surroundings, especially if there are marital, emotional or financial interdependencies. Few persons neither see themselves as a ‘carer’ or ‘family caregiver’ (Sand, 2014), nor identify themselves with the definition by the National Board of Health and Welfare where FC is defined as a person caring for a near one who is long-term sick, elderly or has disabilities (SoS, 2017). It is rather the relation to the person who is ill that one assumes; to be the daughter, son, partner, husband or wife, parent or other relative, neighbour or friend.

As HF is associated with high morbidity, frequent assistance of FCs is needed (Clark et al., 2008, 2014, 2016; Mozaffarian et al., 2016; Pressler et al., 2013). To have a cardiovascular disease such as HF requires those involved to adjust to the new situation and find solutions to the many and various challenges of their near one’s new life conditions (Clark et al., 2014; Dalteg, Benzein, Fridlund, & Malm, 2011; Årestedt, Persson, & Benzein, 2014). Family caregiving includes the provision of emotional, physical and cognitive support and care during the often erratic course of HF with periods of stability, interspersed with exacerbations and unpredictable acute hospitalizations (Kang, Li, & Nolan, 2011; Whittingham, Barnes, & Gardiner, 2013). FCs identify deterioration in the health status of their near one, assess the severity of the illness and whether there is a need for emergency help. FCs also support their near one with care transitions and medical decision-making (Buck et al., 2015; Clark et al., 2008, 2014). FCs have an important role in strengthening their near one’s adherence to a complicated medical treatment, encouraging self-care behaviours and maintenance of a healthy lifestyle (Buck et al., 2015; Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007; Pressler et al., 2013).

Support and care from FCs has been shown to positively affect self-management, leading to fewer hospitalizations, decreased levels of morbidity and mortality for the persons with HF, and an increased HRQoL for both the persons with HF and FCs (Bidwell et al., 2015; Buck et al., 2015; Clark et al., 2014; Salyer et al., 2012; Stamp et al., 2016; Strömberg, 2013; Årestedt, Saveman, Johansson, & Blomqvist, 2013). Also, the emotional well-being of the FCs has been shown to be an independent
predictor of emotional well-being among persons with HF (Ågren et al., 2012). Family caregiving can undoubtedly be rewarding and satisfying as it is an opportunity for increased intimacy and connection with the person who is ill (Duggleby et al., 2010; Strömberg, 2013).

Nevertheless, there is a need to recognize the challenges HF poses for the FCs’ health and well-being, the family function and relationships within the family (Dalteg et al., 2011; Lum et al., 2014; Ågren, Evangelista, & Strömberg, 2010; Årestedt et al., 2014). FCs’ situation and role in relation to a near one with HF is subject to a growing body of research of circa 120 articles, with a majority focusing on the strenuous and negative aspects of caregiving (Dionne-Odom et al., 2017). Family caregiving has been shown to be associated with significant caregiver burden, reduced HRQoL and depression for the FCs (Luttik et al., 2007; Ågren et al., 2010). ‘Caregiver burden’ is a broad term used to describe the emotional, cognitive, physical and financial challenges of providing care. It is related to the disease burden of the person who is ill and the quantity of care given (Hooley, Butler, & Howlett, 2005). Caregiver burden increases due to FC’s eventual own poor health and limited social and professional support (Molloy, Johnston, & Witham, 2005), especially for those in spousal relationships (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Hirst, 2005). Female spouses are thought to be particularly susceptible to depression as a consequence of providing an extensive range of care for their near one. Caregiver burden is also associated with substantial financial losses, particularly for female caregivers (Butler et al., 2005).

The situation of FCs to a person with HF differs from other FCs as the higher prevalence of HF in persons aged over 75 results in a higher age among the FCs who often have their own health problems (Davidson, Abernethy, Newton, Clark, & Currow, 2013; Usher & Cammarata 2009). FCs to a person with HF are also less likely than other FCs to access specialist palliative care services despite reporting greater levels of unmet needs compared to other FCs (Davidson et al., 2013). FCs’ poor health (e.g., exhaustion, anxiety and feelings of uncertainty) negatively affect their near one’s condition and prognosis (Duggleby et al., 2010; Pinquart & Sörensen, 2007). These challenges in family function and relationships within the family need recognition (Dalteg et al., 2011; Kang et al., 2011; Lum et al., 2014; Trivedi, Piette, Fihn, & Edelman, 2012; Ågren et al., 2010; Årestedt et al., 2014). They include changes in family behaviour and communication together with relational incongruence (i.e., lack of communication and/or
inconsistency in perspective) concerning self-care management, monitoring of symptoms and when to seek emergency care (Kitko, Hupcey, Pinto, & Palese, 2015; Retrum, Nowels, & Bekelman, 2013; Strömberg & Luttik, 2015).

Lastly, FCs’ knowledge gaps are reported in the context of medication and symptom management and FCs report little understanding of the HF condition, the aim of treatment and prognosis (Aldred, Gott, & Gariballa, 2005; Boyd et al., 2004; Luttik et al., 2007; Ågren et al., 2012). Most importantly, FCs feel that they do not receive sufficient support or recognition from health care professionals (Aldred et al., 2005; Pihl, Fridlund, & Mårtensson, 2010). Unfortunately, the health care system is shown to be ill equipped to support and facilitate the involvement of FCs in HF care (Kang et al., 2011). Psychosocial and relational support, besides educational interventions, for both persons with HF and their FCs are thus recommended to support and involve families living in the midst of a challenging chronic illness such as HF (Evangelista, Strömberg, & Dionne-Odom, 2016; Hartmann et al., 2010; Sebern, 2005; Strömberg & Luttik, 2015; Wingham et al., 2015).

In this thesis, family caregiving is defined as help, support and care from family members (see definition of family in section 2.3) and includes medication management and self-care activities, navigating health care and government contacts, monitoring illness-related symptoms and providing emotional and social support. Family caregiving also applies to domestic work, planning of activities, shopping, transportation, managing paperwork and finances, as well as helping with personal hygiene and clothing.

2.3 Theoretical perspectives

No particular theoretical standpoint or framework were held prior to formulating the research questions in studies I and II. During the analysis of study II and the planning of study III, I came to understand the importance of RNs addressing the quality of the relationship between the person with HF and their FC and thus the need to involve both in their daily work. The persons in a dyad affect each other reciprocally, which will influence their management of the HF condition. After studying the literature on dyadic incongruence, relationship quality and family nursing, I found the theoretical perspective of FSN to be appropriate for my research. FSN, with its system
theory perspective, and the Illness Belief Model (IBM) used in nursing practice with families, problematized my research questions in an explicatory and appealing way. Together with the Swedish family-focused nursing, they inspired me to conduct the Family Health Conversation (FamHC) intervention in study IV.

Wright and Bell (2009) define a family as a group of individuals who are bound by strong emotional ties, a sense of belonging and a passion for being involved in one another’s lives. Wright and Leahey (2013, p.55) found the following definition to be useful in their clinical work: The family is who they say they are. With this definition the RNs can honour individual family members’ ideas about which relationships that are significant to them and their experience of health and illness. Yet another definition of family is valid and adopted in FSN: the family is a self-identified group of two or more individuals whose association is characterized by special terms, who may or may not be related by bloodlines or law, but who function in such a way that they consider themselves to be a family (Whall, 1986, p.241). All of these definitions allow individuals who neither share a household nor are related by blood or have legal ties to constitute a family. Each individual thus decides who is a member of one’s family.

2.3.1 Family Systems Nursing

FSN was developed in Canada by Lorraine Wright and Maureen Leahey in 1990, and describes a focus on the interaction, reciprocity and relationships between multiple systems levels; individual, family and larger systems (Bell & Wright, 2015). The overall aim of FSN is to sustain health and promote healing and more specifically to change, improve and/or maintain family functioning (Bell & Wright, 2015; Wright & Leahey, 2013). FSN and IBM used in the nursing practice with families, are built on a postmodernist worldview and several theoretical foundations: systems theory, communication theory, and change theory. Furthermore, there are various assumptions and premises for FSN, which include human beliefs in a multiverse reality, and reflection and sharing narratives as means to change beliefs and the nurse-family relationship (Wright & Bell, 2009; Wright & Leahey, 2013).

The core assumption of FSN is that health and illness affect all members of a family and the individuals find themselves in a system in which changes in one part, or individual, affect the others (Wright & Leahey, 2013). Systems
theory helps to explain the reciprocal interaction within the family, which represents a system where all parts interact and the whole is greater than the parts (Bateson, 1998; Óquist, 2013). This reciprocity means for example that if the person in the family who has an illness is nevertheless feeling well, the family members will also feel well. The family can thus contribute to reduced suffering, enhanced health and well-being for all in the family. It may also be opposite; the family may contribute to increased suffering and ill health. The interplay and the relationships between the family members’ beliefs and experiences are in focus in FSN, rather than on the individual family members themselves. This entails that the ‘problem’, or what the family identifies as hampering their family health, resides in the dialogue between individuals instead of within individuals. It is the communication about the problem that identifies its focus and boundaries as well as the people related to the present problem. The systems theory perspective can shift focus from individual parts to the whole and vice versa. Focus can be on both the parts/individuals and the whole/family simultaneously; it is not an either/or focus but rather a both/and (Wright & Leahey, 2013).

In FSN, the function of communication is for RNs to assist family members in clarifying family rules regarding behaviour, to help them learn about new conditions, to explicate how conflicts can be resolved and to nurture and develop self-esteem among all family members (Wright & Leahey, 2013). It is a process in which the family and the RN jointly create meaning, which is understood and changed while interacting with one another (Andersen, 2011). Relations systems tend to change when illness and disease occur, which is why change theory is also central in FSN. When a system is changing it strives for stability and when stability is reached, the system again strives for change. The persistence and change are always connected to each other and must be considered together despite their opposing natures (Wright & Leahey, 2013; Óquist, 2013).

2.3.1.1 Beliefs in a multiverse reality
Overall, the most important theoretical and ontological assumption in FSN is the outlook on mankind and the concept of truth, how we view the world, and that the same reality can be perceived differently by different people. According to Maturana (1988), reality consists of not one universe but a multiverse, meaning that there is a ‘multiverse reality’. This is essential to understand when establishing relationships with families. If each family member’s view is to be acknowledged as equally valid, it calls for
recognition that the same event, situation and activity can be perceived in different ways. This means that if two people describe a specific situation in different ways, both their descriptions are equally true and/or probable. No ‘truth’ is therefore more valid than another. Every single event or phenomenon can be understood in different ways that affects our thoughts, feelings and behaviours in different ways. This view is linked to the assumption that our beliefs are taken to be the truths of a subjective reality that influences how individuals experience reality and construct their lives (Wright & Bell, 2009).

The IBM is a nursing model for practice with families, based on the principle that it is not necessarily the illness but rather the beliefs about the illness that are potentially the greatest source of individual and family suffering. Beliefs refer to fundamental attitudes, premises, values and assumptions held by individuals and families. Beliefs are vital in FSN as our beliefs about health are challenged, threatened or affirmed when illness arises. Beliefs can be defined as the lenses through which we view the world and they guide us in choices we make, behaviours we choose and feelings with which we respond (Wright & Bell, 2009, p.19). Our core beliefs, which are often unspoken, are fundamental to our identity. We live our lives by our beliefs and they are often accompanied by affective and physiological reactions. Core beliefs are powerful and influence response to illness and family functioning. Beliefs emerge, develop, and change through our interactions with others in different contexts such as culture, religion, workplace and family. We influence each other’s beliefs and develop our identity through the belief systems that we share, or do not share, within families and friendships. Illness beliefs can be both facilitating and constraining. By constraining beliefs, Wright and Bell (2009) refer to beliefs that reduce solution options and often enhance suffering, whereas facilitating beliefs can ameliorate illness suffering and increase solution options to manage the illness. Constraining and facilitating beliefs have a predictive effect on perceptions and action, and they impact on both the RN and the family involved in the process. However, being aware of and daring to challenge these beliefs can result in positive changes (Wright & Bell, 2009).

Through reflective processes, unconscious and unreflected beliefs may become part of a conscious awareness. Reflection helps to create new insights and understanding of one’s own and others’ perspectives and is used for health-promoting purposes in FSN. Andersen (2011) describes how reflection can include ideas, thoughts and feelings related to what is
occurring in the conversation, and proposes a slow conversation and to use pauses. Bateson (1998) describes that it is through acknowledging and reflecting upon the differences between one’s own and others’ beliefs and experiences of reality that the individual’s personal beliefs continuously evolve. It is ‘the difference that makes a difference’ as knowledge about ourselves and others, in consequence, changes.

2.3.1.2 Relationship between family members and the registered nurse
FSN values collaborative, non-hierarchical relationships between the family members and the RN. All are acknowledged as equal partners and the interaction is characterized by reciprocity. Such a relationship is an essential prerequisite for a positive outcome, as is the establishment of a trustful relationship and a calm and relaxing atmosphere. FSN involves a development of the RNs’ perception and relationship to family members, as RNs’ own perceptions about their profession may be challenged. Each encounter the RN has with the family needs to be tailored to the specific family and their challenges. The RN and the family have different skills as regards how health can be preserved and how health problems can be addressed. Both the RN and the family take their particular strengths and resources into the health care meeting and learn about each other’s beliefs and competencies (Wright & Leahey, 2013).

2.3.2 Family-focused nursing
Family-focused nursing was developed by researchers in Sweden at the Linnaeus University in Kalmar and Umeå University in Umeå (Benzein, Hagberg, & Saveman, 2012; Saveman, 2010; Saveman & Benzein, 2001) with influences from the FSN and the IBM described in section 2.3.1. Family-focused nursing can be either family-related or family-centred. In the family-related nursing, the person with the illness, or the FC, or the RN, is in focus and the others represent the context. This was the approach held in studies I, II and III. The family-focused nursing that rests on a systemic approach is called family-centred nursing, and was the approach held in study IV. The aim of a family-centred approach is to establish a partnership with the family in a joint effort to promote health and to prevent ill health and suffering.

2.3.2.1 Family Health Conversation
FamHC is a nursing intervention developed within family-centred nursing (Benzein et al., 2008; Saveman, 2010). FamHCS’ purpose is to create a
context for change. They primarily build on a salutogenic approach, which focuses on the family’s internal strengths and external resources. The salutogenic approach as proposed by Antonovsky (1987) has been adopted in FamHC since this approach sees human nature as heterostatic rather than homeostatic and health is seen as a process rather than a static state. Health care, in general, uses the pathogenic approach which focuses on what has caused the disease or illness. Salutogenes focuses on health and highlights factors that make us feel good and that create and maintain health, rather than factors that cause disease. This means that the question is: “why do people stay healthy” instead of “why do people become ill”. FamHC, involves lifting the family’s strengths and resources rather than focusing on disease and illness. All families have strengths and resources but their beliefs and experiences of illness may hinder their ability to recognize them. Thus, the aim is to create a context for change; to create new beliefs, new ideas and new meanings and possibilities in relation to family problems and thus shift illness beliefs from disease and suffering to positive aspects and well-being (Mittelmark & Bull, 2013). Hopefully, the family then finds alternative ways of looking at their situation and eventually explores new solutions (Benzein et al., 2008).

The RN’s approach is of paramount significance in FamHCS and has similarities to, and is built on the same grounds as, the person-centred approach (Ekman et al., 2011) with the addition of a systemic approach in which all parties influence each other in different directions (Öquist, 2013). To see the other as a person also means being able to understand the other’s subjective world, thus to listen to each family member’s narrative is the starting point in the FamHCS. Telling one’s own story has great healing potential and is closely intertwined with reflection. In creating one’s own story through narratives, the family members define themselves (Ricoeur, 1991), which helps family members in FamHCS to comprehend the other family members’ perceptions. A reflected on story is not intended to describe an event exactly but to try to find new meanings and detect new associations which can lead to change (Andersen, 2011; Benzein et al., 2008). Through sharing one’s own narrative and listening to others’ a better understanding is created for how oneself and others perceive reality. To have the possibility to narrate one’s lived experiences is a way of finding meaning in one’s life, of shaping one’s identity and a way of understanding oneself (Ricoeur, 1991).
In FamHCs, no one takes precedence over the others’ experiences and competencies as they are all given equal importance (Benzein et al., 2008, 2012). The family members have the preferential right to decide what to talk about in FamHC and the RNs listen and try to discern the essential parts of the narratives. It is not the RN’s role to give directions, to lecture, demand or insist on specific changes that the RN wants the family to make. Rather, the RN creates a collaborative environment by providing support through a genuine interest in the family’s perceptions and beliefs. In this way, FamHC consists of what families wish to talk about, and the RN takes a participatory position in the conversation rather than an influencing one (Benzein et al., 2008; Wright & Leahey, 2013).

In FamHCs, the RNs focus on strengths and invite curiosity and reflection through asking reflective questions (Andersen, 2011; Benzein et al., 2008; Brown, 1997; Wright & Bell, 2009; Wright & Leahey, 2013). These questions focus on relationships and are ‘appropriately unusual’; they open up new questions and directions of thinking as they are slightly different from the families’ own beliefs and reflections, but not too different (Andersen, 2011). In order to let the most significant perceptions and experiences emerge, questions that focus on differences are used, for example “What have you learned that works to assist you with all of your demands?”, “What worries you the most in the family?”, “What is the biggest difference in your relationships in family life now compared to before the onset of your mother’s heart failure?”, “Who in the family takes the greatest responsibility for your medication management?” During the FamHCs, silence is sometimes used purposively to give time for reflection and new thoughts and ideas to emerge and be voiced. During the FamHCs, differing perceptions can arise among family members and the RN’s role is to embrace them all without partiality.
HF is an increasingly prevalent, chronic and progressive condition associated with high morbidity and mortality, which necessitates frequent assistance of FCs. To have a cardiovascular disease such as HF requires those involved to adjust and cope with the person’s new lifestyle, and support the treatment regimen. Family support has been shown to positively affect self-management and health outcomes, and HRQoL for both the person with HF and FC. It also leads to fewer hospitalizations and decreased levels of mortality. Family caregiving can undoubtedly be rewarding and satisfying as it represents an opportunity for increased intimacy and connection with the person who is ill. Nevertheless, there is a need to recognize the challenges HF poses to FCs’ health and well-being, family function and relationships within the family.

RNs frequently meet the FCs to a person with HF in hospital settings and in PHCCs and have a key role in meeting the needs of FCs. The quality of these encounters is likely to be influenced by the attitudes RNs hold towards FCs’ role and involvement in HF nursing care. To have positive and supportive attitudes towards FCs’ involvement is essential for inviting and involving families in nursing care, while negative attitudes lead RNs to minimize family involvement. Family involvement in HF nursing care has been shown to alleviate the family’s suffering and to strengthen family bonds, and can be an opportunity for RNs to develop a closer and more constructive relationship with the persons with HF and FCs. However, in practice, HF nursing interventions primarily focus on the person with HF. Given the importance of family caregiving in HF and the role RNs can play in supporting FCs in their caregiving, there is a need to explore RNs’ attitudes towards families’ involvement in the specific area of HF nursing. Furthermore, there is a need to explore a psychosocial and relationship focused intervention for both persons with HF and their FCs, with the goal of sufficiently supporting families facing a challenging chronic illness such as HF.
4 AIMS

Overall aim
This thesis aims to explore the situation and needs of family caregivers to a person with heart failure, and to explore the requisites and ways of supporting and involving family caregivers in heart failure nursing care.

Specific aims
- To explore informal caregivers’ experiences and needs when caring for a relative with heart failure living in their own home. (I)

- To explore registered nurses’ perceptions about the situation of family caregivers to patients with heart failure living in their own home, and registered nurses’ interventions to improve family caregivers’ situation. (II)

- To explore registered nurses’ attitudes toward the importance of families’ involvement in heart failure nursing care and to identify factors that predict the most supportive attitudes. (III)

- To explore the experiences and feasibility of registered nurses’ Family Health Conversations via telephone with persons with heart failure living in their own home, and their family caregivers. (IV)
5 METHODS

5.1 Study settings

5.1.1 Organization of health care in the Region of Västmanland

In 2012, the responsibility for home health care was transferred from the region’s, then called county council, PHCCs to the municipalities. The shift is in line with 20 of Sweden’s 21 regions/county councils. The municipality is now responsible for the health care provided in the homes of persons who, due to illness or disability, are not able to seek care at the PHCCs. This is called the threshold principle. Deviations from this principle can be made when the person’s illness, disability or social circumstances so warrant. The region is still responsible for health interventions during the person’s visits to PHCCs and for physicians’ medical interventions in home care (VKL, 2012a; VKL, 2012b).

The region recommends that persons with a clear aetiology of HF who respond favourably to treatment and where surgical or catheter-borne interventions are not planned, can be managed in primary health care. Even persons with advanced HF can be managed in primary health care if the symptoms are stable and no surgical interventions are relevant. The ‘most ill older persons’ with HF where transport to the hospital poses major problems, can receive follow-ups in their own home with, for example, weekly weight check-ups, and can obtain dose adjustments of medications, either through the municipality or the hospitals’ advanced home health care team (Region Västmanland, 2015).

Conducting the research in the region of Västmanland was a result of convenience sampling. Compared to the national average, the region of Västmanland has a higher number of hospital admissions for persons with HF, but a lower number of readmissions to hospital (SoS, 2009, 2015c).
5.1.2 Health care units in Västmanland County (I+II+IV)
Västmanland county has approximately 267,000 inhabitants. In the county there are four hospitals, three region-run and one privately run. The region-run hospitals are those in Västerås, Köping and Sala and were included in three of the four studies. The hospital in Västerås is the county hospital with access to all resources of an emergency care hospital, which involves instant access to the surgical department, intensive care, radiology and several specialties. The health care provided by the hospitals outside of Västerås is usually planned in advance. It offers access to fast and close contacts; however, they do not have the resources to qualify as emergency care hospitals. All hospitals have nurse-led HF clinics (Region Västmanland, 2017).

There are 29 PHCCs in the county, of which 12 are region-run and 17 are privately run. The privately run PHCCs have agreements with the region and operate in the same way as the region-run PHCCs. Three of the 29 PHCCs were included in study II. One of the 29 PHCCs has a nurse-led HF clinic (Region Västmanland, 2017).

5.1.3 Health care units in Sweden (III)
Health care units that report patient data to The Swedish Heart Failure Registry (SwedeHF) were eligible for inclusion in study III (SwedeHF, 2015). SwedeHF was created in 2003 and, at the time of the study, had 132 participating units - 58 hospitals and 74 PHCCs. A total of 75% of the hospitals and 10% of the PHCCs are participating units. Registration is carried out on hospital admissions, at outpatient visits and annually thereafter. SwedeHF is funded by the Swedish Association of Local Authorities and Regions and is considered a valuable tool for improving the HF management (Jonsson, Edner, Alehagen, & Dahlström, 2010). Two of the four hospitals in Västmanland county report to SwedeHF (Västerås and Köping) and none of the PHCCs do (SwedeHF, 2015).

5.2 Overview of study design
Qualitative and quantitative methods have been combined in a complementary way in this thesis (Table 1). The specific research methods were chosen with regard to the aims and research questions in the different studies. The research process of the thesis followed an emergent design as
the findings in studies I and II formed the basis for the rationale of study III, which in turn formed the rationale for study IV.

Studies I and II aimed to explore FCs’ situation when caring for a person with HF from the FCs’ perspective and from the perspective of RNs. The research questions were open-ended because there is relatively little knowledge about FCs’ needs and RNs’ perceptions about the FCs’ situation and ways of improving their situation. A qualitative method with an inductive approach and an explorative design therefore seemed appropriate, given its exploratory and probing-oriented approach (Creswell, 2009). When learning about RNs’ perceptions in study II, the question arose of whether RNs’ perceptions were specific to RNs in the present county, or perhaps transferrable to other RNs working with HF nursing care in Sweden. In searching for an answer, the planning of the nationwide web-survey study III commenced. As I was interested in which factors that were associated with, and also predicted, RNs’ positive attitudes towards FCs in HF nursing care, a quantitative design was chosen. Lastly, when working on study III, I became familiar with the advantages of FamHCs. I found them suitable for my area of research, yet they were scarcely used, which led me to explore them in the intervention study IV.
Table 1. Overview of study design

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
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<tbody>
<tr>
<td>Design</td>
<td>Interview study (Qualitative)</td>
<td>Interview study (Qualitative)</td>
<td>Web-survey study (Quantitative)</td>
<td>Single group intervention study with a pretest-posttest design (Quantitative and Qualitative)</td>
</tr>
<tr>
<td>Specific aim</td>
<td>To explore informal caregivers’ experiences and needs when caring for a relative with heart failure living in their own home.</td>
<td>To explore registered nurses’ perceptions about the situation of family caregivers to patients with heart failure living in their own home, and registered nurses’ interventions to improve family caregivers’ situation.</td>
<td>To explore registered nurses’ attitudes toward the importance of families’ involvement in heart failure nursing care and to identify factors that predict the most supportive attitudes.</td>
<td>To explore the experiences and feasibility of registered nurses’ Family Health Conversations via telephone with persons with heart failure living in their own home, and their family caregivers.</td>
</tr>
<tr>
<td>Participants</td>
<td>Family caregivers (n=14) to a person with heart failure in the cardiac outpatient clinic in a county hospital.</td>
<td>Registered nurses (n=23) in hospitals (n=3) and primary health care centres (n=3) in one county.</td>
<td>Registered nurses (n=303) working with persons with heart failure in hospitals (n=47) and primary health care centres (n=30) in Sweden.</td>
<td>Registered nurses (n=5), persons with heart failure (n=8) and their family caregivers (n=8) in nurse-led heart failure clinics (n=3) in one county.</td>
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<tr>
<td>Data collection</td>
<td>Semi-structured individual interviews.</td>
<td>Semi-structured focus group interviews.</td>
<td>Questionnaires</td>
<td>Questionnaires and semi-structured individual and joint interviews.</td>
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<td>Data analysis</td>
<td>Qualitative content analysis with an inductive approach.</td>
<td>Qualitative content analysis with an inductive approach.</td>
<td>Descriptive and inferential statistics.</td>
<td>Descriptive statistics and qualitative content analysis with a deductive approach.</td>
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</table>
5.3 Participants, procedures and data collection

5.3.1 Individual interviews with family caregivers (I)

In study I, semi-structured individual interviews (Kvale, 1996; Kvale & Brinkmann, 2009) were conducted with 14 FCs - eight female spouses, three male spouses and three daughters. The spouses were co-habiting with the person with HF, whereas the daughters were not. The FCs’ age ranged between 50 and 88 years and they had provided care to their near one for between one month and 20 years. The age of the persons with HF ranged between 68 and 93 years.

The FCs were recruited by RNs in the cardiac outpatient clinic in the county hospital. FCs were included in the study if they cared for a person aged 65 years and older who lived in their own home and had been hospitalized with HF as the primary diagnosis during the past three months. Of the 42 FCs that were contacted, through contact details given to the RNs by the persons with HF at a routine telephone follow-up, 14 agreed to participate. Reasons given for not participating were not having anything useful to contribute, being short of time, or experiencing ill health themselves.

The interviews were conducted at a location of the FCs’ preference; in the FCs’ homes and two different neutral places in the city. A semi-structured interview guide (see paper I) was used, with open-ended questions, follow-up questions and probes when needed (Kvale & Brinkmann, 2009). The interview guide was developed by the research group based on the literature on family caregiving and HF (Kang et al., 2011; Molloy et al., 2005). An inductive approach was used and the FCs were asked to freely describe and reflect on different situations of caregiving; their role as caregivers and how it affected the relationship with their near one with HF and life in general; their needs and how these could best be met; and lastly their encounters with health care.

All interviews were performed, digitally recorded and transcribed verbatim in their entirety by the author (Holloway & Wheeler, 2010; Kvale & Brinkman, 2009). The transcriptions were verified by the research group.
5.3.2 Focus group interviews with registered nurses (II)

With the aim of exploring wide-ranging perceptions and experiences, focus group interviews (FGIs) were used in study II. This mode of data collection has been shown to elicit rich information through the dynamics and interaction generated within the group (Krueger & Casey, 2015). Six FGIs with three to five participants per group (Barbour, 2007; Holloway & Wheeler, 2010) were conducted with 23 RNs; 10 RNs from three hospitals and 13 RNs from three PHCCs. The RNs’ median age and overall professional experience in the hospitals were 10 years less than for RNs in PHCCs (see paper II for further demographics).

Managers in the three region-run hospitals in the county were asked, and agreed, to participate in the study. In the county there are 29 PHCCs. Of the 12 PHCCs who met the inclusion criterion of having a minimum of 2000 listed persons who were 65 years and older, six were randomly selected. Managers in these six PHCCs were asked about participation and three agreed to participate in the study. RNs were included in the study if they (1) worked at an eligible PHCC or, (2) worked in the medical clinic in the hospital and, (3) had worked at the present health care unit for a minimum of one year. All included RNs worked with persons with HF on a daily basis.

For practical reasons all FGIs were conducted in the RNs’ respective workplaces. A semi-structured interview guide (see paper II) was used, with open-ended questions and follow-up questions and probes when needed (Krueger & Casey, 2015; Kvale & Brinkmann, 2009). The interview guide was developed by the research group based on the literature on family caregiving and HF (Kang et al., 2011; Molloy et al., 2005). An inductive approach was used and the RNs were asked to freely describe and reflect on different experiences from encounters with FCs to a person with HF. The author was the moderator and balanced the FGIs so that all questions in the interview guide were evoked. An assistant moderator took observational notes and helped to recapture and summarize points of particular relevance to the study aims at the end of each interview. The RNs then reflected on, verified and further developed the content, which is a recommended method of validation of FGIs (Krueger & Casey, 2015).

All interviews were performed, digitally recorded and transcribed verbatim in their entirety by the author (Holloway & Wheeler, 2010; Kvale & Brinkman, 2009). The transcriptions were verified by the research group.
5.3.3 National web-survey with registered nurses (III)

Study III was a cross-sectional, multicentre web-survey study, using the validated and psychometrically tested Swedish instrument Families’ Importance in Nursing Care - Nurses’ Attitudes (FINC-NA) (Saveman, Benzein, Engström, & Årestedt, 2011). The RNs working in Swedish hospitals (n=64) and PHCCs (n=111) that during the past six months had registered patient data in The Swedish Heart Failure Registry (Jonsson, Edner, Alehagen, & Dahlström, 2010; SwedeHF, 2015) were eligible for inclusion. Managers in these health care units were contacted by email, informed about the study, and asked to provide contact information for RNs working with persons with HF. The single inclusion criterion for RNs was that they should work with persons with HF on a daily basis, irrespective of whether their workplace was a hospital ward, a cardiac/medical outpatient clinic, a nurse-led HF clinic, a PHCC or in home health care. A total of 100 managers from 54 hospitals and 58 PHCCs replied with contact information for 540 RNs. These RNs were sent an information email which contained the embedded link to the survey, administered by the Netigate® software (2015).

Data were collected from 317 RNs, a response rate of 59%. A total of 14 responses only contained demographic data and were excluded from the analyses. Thus, the analyses were performed on responses from 303 RNs from 47 hospitals and 30 PHCCs. Demographic data of the respondents was collected (see paper III) and RNs received the instrument FINC-NA (Saveman et al., 2011) which consists of 26 items and two generic questions (see paper III). FINC-NA has four subscales: Family as a Resource in Nursing Care (Fam-RNC), Family as a Conversational Partner (Fam-CP), Family as a Burden (Fam-B) and Family as its Own Resource (Fam-OR). Scores for subscale Fam-B were reversed before analysis. Alternatives are rated on a 5-point Likert scale, ranging from ‘Totally disagree’ to ‘Totally agree’. Higher scores reflect having more supportive attitudes towards family involvement in nursing care. The score for Total scale is 130 points (Fam-RNC, 50 points; Fam-CP, 40 points; Fam-B, 20 points and; Fam-OR, 20 points). In the present study, internal consistency was Cronbach’s alpha .86 for Total scale, .87 for Fam-RNC, .79 for Fam-CP, .71 for Fam-B and .79 for Fam-OR. The FINC-NA has previously been found to be reliable and valid (Saveman et al., 2011).
5.3.4 Family Health Conversation intervention with family caregivers, persons with heart failure and registered nurses (IV) RNs’ FamHCs via telephone were explored in the intervention study IV. Data were obtained via two questionnaires and three single statements pre and post intervention, and eight interviews post intervention.

In the present county all three region-run hospitals, which had a nurse-led HF clinic or designated time for follow-up of persons with HF, were included. Participants in the study were five RNs, eight persons with HF and eight FCs. The inclusion criterion for the RNs was that they worked in the aforementioned clinics. Inclusion criteria for persons with HF were; 1) being registered for follow-up visits in the nurse-led health care clinic for at least one year and, 2) diagnosed with HF in NYHA classes 2 or 3. Inclusion criteria for both persons with HF and FCs were; 1) having the ability to speak and understand the Swedish language and, 2) having a telephone with speakerphone capability.

The five RNs took part in a specially constructed half-day intensive course held by the author who is trained in conducting FamHCs. The course covered the theory and the core components of the practice of FamHCs (Benzein et al., 2008, 2012). After the course, the RNs conducted three FamHCs with each family for an average of 45 minutes (range 30-60 minutes) every two weeks using a telephone with speakerphone capability. The FamHCs in the present intervention differed from the original FamHCs, which are conducted by two RNs who meet in person with the family and a closing letter is sent to the family two-three weeks after the last FamHC (Benzein et al., 2008, 2012).

To assess and ensure RNs’ fidelity to the core components of FamHCs (Östlund, Bäckström, Lindh, Sundin, & Saveman, 2015), the author listened to each RN’s first and third FamHC with each family. The families were informed about the author’s presence in the room, and the reason for it, and gave their verbal consent. Immediately after concluding the first FamHC, the RN and author discussed the process and fidelity to the core components of the recently performed FamHC, and the RN was provided with guidance to appropriately prepare for the next FamHC with the same family.

In the FamHCs, RNs asked about the family’s expectations regarding the conversations and invited each family member to give their narratives and describe their beliefs that they held about the current situation. After the
family members had listened to one another’s stories, the RNs invited reflection by asking “What are your thoughts after having listened to your daughter’s/husband’s/wife’s/mother’s experience of your family’s situation?” The RNs listened carefully and tried to discern the essential parts of the narratives, and together with the family prioritized which problem/s that needed to be discussed. The RNs also posed reflective questions with the intention to invite reflection on the family’s strengths and resources and support change, see previous section 2.3.2.1. During the FamHCs, silence was used purposively, to give time for new thoughts and ideas to emerge and be voiced.

The purpose of the second FamHC was to go deeper into the family’s situation and questions that initiated the second FamHC were: “What has happened since the last time we talked?” and “What is most appropriate for you to talk about today, considering what you’ve been thinking about since our last conversation?” In the third and last FamHC, the purpose was to visualize the family’s thoughts about the future. The third FamHC was similar to the previous two, but focused more on the future. The third FamHC also ended the series of FamHCs, thus the RNs together with the family summarized and reflected on the eventual process of change that the family had undergone. At the end of each FamHC, RNs offered their commendations and own reflections to the family, which validated or normalized the family’s narratives and emotional responses. The RNs were also explicit about the FamHCs’ intention not to be solution-focused. Rather, they focused on the family’s ability to develop their own tools to reduce suffering and improve well-being. The problem might persist but the family may have found new strategies to help them live with and manage their situation.

5.3.4.1 Quantitative data collection
Quantitative measures were used to explore the first and second specific aims before and after RNs’ FamHCs via telephone, namely: (1) FCs’ experience of caregiver burden, and (2) families’ experience of RNs’ support, and of communication within the family. To explore these aims, two questionnaires and three single statements were used.

Heart Failure Caregiver Questionnaire (HF-CQ®)
The Heart Failure Caregiver Questionnaire (HF-CQ®) is a validated and psychometrically tested instrument which aims to assess the subjective caregiver burden of FCs to persons with HF (Strömberg et al., 2017).
Questions were answered by FCs, using a recall period of the past four weeks. ‘Care’ was defined as all unpaid help. The HF-CQ® consists of 21 questions, divided into three domains: Physical well-being (five questions), Emotional well-being (11 questions) and Lifestyle (five questions). Alternatives are rated on a 5-point Likert scale, ranging from ‘Not at all’ to ‘Very much’. Higher scores reflect a higher subjective burden associated with caregiving. The total score for the entire scale is 100 points (Physical health, 25 points; Emotional well-being, 55 points and; Lifestyle, 20 points). The HF-CQ® has previously been found to be reliable and valid (Strömberg et al., 2017).

Communication
FCs and persons with HF were given three statements assessing communication between family members using a recall period of the past four weeks (Fried, Bradley, O’Leary, & Byers, 2005):

- It is important to me to talk to my near one about my illness/my near one’s illness.
- I would like to talk to my near one about my illness/my near one’s illness more than I have done.
- It is difficult for me to talk to my near one about my illness/my near one’s illness.

For the above three statements, alternatives were rated on a five-point Likert scale, ranging from ‘Not at all’ to ‘Very much’. The statements were independently translated by three research colleagues from English to Swedish and back-translated twice, whereon reconciliation of back-translation and a harmonized translation of the Swedish version was achieved.

Iceland-Family Perceived Support Questionnaire (ICE-FPSQ (Swe))
ICE-FPSQ (Swe) is a translated and reliability and validity tested questionnaire (Bruce et al., 2016), of the Icelandic ICE-FPSQ (Sveinbjarnardottir, Svavarsdottir, & Hrafnkelsson, 2012). The ICE-FPSQ (Swe) was answered by persons with HF and FCs with the aim of assessing their perceptions about cognitive and emotional support from RNs. The theoretical basis for the ICE-FPSQ is the earlier described FSN, developed by Wright and Leahey (2013). It consists of 14 items that are divided into two subscales: Cognitive support (five items) and Emotional support (nine items). Alternatives are rated on a 5-point Likert scale, ranging from ‘Almost never’ to ‘Almost always’. Higher scores reflect a perception about
consistent family support offered by the RNs. The total score for the entire scale is 70 points (Cognitive support, 25 points and Emotional support, 45 points). The ICE-FPSQ and ICE-FPSQ (Swe) have previously been found to be reliable and valid (Bruce et al., 2016; Sveinbjarnardottir et al., 2012).

5.3.4.2 Qualitative data collection

Qualitative inquiry was used to explore the third and fourth specific aims: (3) families’ and RNs’ experiences of FamHCs, and (4) families’ and RNs’ perceptions about the feasibility of conducting FamHCs via telephone. A semi-structured interview guide was used with questions inspired by Benzein and colleagues (2015) (see paper IV).

As a deductive approach was used, an open-ended question was first asked, followed by targeted questions within predefined categories (Hsie & Shannon, 2005). These categories corresponded to the anticipated results of successful FamHCs (see bold text in interview guide in paper IV) (Benzein et al., 2015; Benzein & Saveman, 2008; Dorell, Bäckström et al., 2016; Dorell, Isaksson et al., 2016; Dorell & Sundin, 2016; Dorell, Östlund et al., 2016; Sundin et al., 2016; Östlund et al., 2016). A predefined category on the feasibility of conducting FamHCs via telephone was also added. When needed, follow-up questions and probes were used for clarification (Kvale & Brinkman, 2009).

Interviews with families

Five joint interviews were performed with five families four to six weeks after their last FamHC. A joint interview is defined as an interview conducted by one researcher with two people who have a prior relationship (Polak & Green, 2016). Joint interviews present a unique opportunity to support dynamic communication between informants (Morgan, Ataie, Carder, & Hoffman, 2013). The interviews were performed in the family’s home and lasted 45-70 minutes.

Interviews with registered nurses

One individual and two joint interviews were performed with all five RNs after completion of the FamHC series. The interviews were performed in the RNs’ respective workplaces and lasted 20-30 minutes.

All interviews were performed, digitally recorded and transcribed verbatim in their entirety by the author (Holloway & Wheeler, 2010; Kvale & Brinkman, 2009). The transcriptions were verified by the research group.
5.4 Data analyses

5.4.1 Qualitative content analyses (I+II+IV)

Content analysis has a history of variable usage both quantitatively and qualitatively. It originally focused on the location of a range of variables, such as specific words, followed by a quantitative analysis using statistics. Qualitative content analysis, by contrast, is about recognizing patterns and condensing data (Patton, 2015). In the 21st century, qualitative content analysis has been increasingly applied in nursing research and is used to provide a thick description of a phenomenon (Elo & Kyngäs, 2008). It has significantly added to the knowledge about human experiences of health issues and illnesses (Hsieh & Shannon, 2005). Similar to thematic analysis, one of the many benefits of qualitative content analysis is its flexibility and independence of theory and epistemology and it can thus be applied across a range of theoretical and epistemological approaches. Through its theoretical freedom, qualitative content analysis provides the researcher with a robust and flexible, yet systematic, tool for analysing qualitative data (Braun & Clarke, 2006, 2014).

The overall procedure in qualitative content analysis is based on a process of organising text into codes, categories and themes along with corresponding patterns, to gain knowledge and understanding about a certain phenomenon (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Polit & Beck, 2014). The text can be analysed on a descriptive level, which refers to the manifest content of the text and describes the visible and obvious parts of the text. It can also be analysed on an interpretative level, which refers to the latent content of the text and deals with interpretation of the underlying meanings of the text (Graneheim & Lundman, 2004; Krippendorff, 2013). However, in practice the distinction between the descriptive and the interpretative level is often seen as a continuum from highly manifest to highly latent (Neuendorf, 2002). Graneheim and Lundman (2004) argue that both levels deal with interpretation but they vary in the depth and level of abstraction; the two levels are not seen as mutually exclusive. During the analysis process there is a constant movement back and forth between various levels of abstraction and between the whole and parts of the text. The question of what level patterns are sought at, and what interpretations are made of those patterns, are left to the researchers (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004).
In this thesis, qualitative content analysis with both an inductive approach (I-II) (Graneheim & Lundman, 2004) and a deductive approach (IV) (Elo & Kyngäs, 2007; Hsie & Shannon, 2005) was used. The research question, the amount of previous knowledge and the eventual existence of a framework or theory determined which of the two approaches to choose.

In the analysis in studies I and II, the transcripts of the interviews were read several times to get a general sense of the text. Coding, categorization, and thematisation were carried out inductively in several stages. First, meaning units were identified and condensed in the original text material and labelled with codes on a descriptive level. The codes were compared for similarities and differences and sorted into categories. In study I, the analysis continued with a cross-category search to identify recurring regularities, expressed as themes at an interpretive level. Throughout the analysis, the research group went back and forth between the interviews, codes, categories and themes to validate the results. Each step of the analysis was discussed at regular meetings until consensus was achieved.

A deductive approach was chosen in study IV since a model and theory existed prior to collecting data. The intention was to explore the already existing model of FamHC but in new and different contexts; in HF nursing care and using telephone instead of meeting in person (Hsieh & Shannon, 2005). The data was thus viewed in a specific way; in search for specific issues or categories related to the model and theory in use. The coding framework consisted of predefined categories corresponding to questions in the interview guide (see bold text in interview guide in paper IV). First, the transcripts of the interviews were read through to get a general sense of the text as a whole, and the sections with the families’ and RNs’ experiences of FamHCs and perceptions about feasibility were highlighted. The highlighted text was then coded, and placed into the predefined categories of the coding framework. Data that could not be coded within the predefined categories were given new categories (Hsieh & Shannon, 2005).

The transcribed material in studies I and II was imported into the QSR NVivo10 software program for management purposes. The transcribed material in study IV was smaller in quantity and thus manually manageable. The author was responsible for the coding and categorization of the data but worked closely with the research group.
5.4.2 Statistical analyses (III+IV)

Descriptive statistics were performed in studies III and IV. In study III, descriptive statistics of demographic data for RNs were calculated. One-sample Kolmogorov–Smirnov test was used to compare means. A Mann Whitney U test was used to analyse differences between two subgroups and a Kruskal-Wallis test was used to analyse differences between three or more subgroups. A list view deletion of 14 cases who did not respond to any of the FINC-NA items was carried out (from 317 cases to 303 cases). Other missing values for scores in FINC-NA were 2% and imputation of item mean score was used (Huisman, 2000). In study IV, descriptive statistics of demographic data for families were calculated. A paired t-test was used to compare means pre- and post-intervention.

Inferential statistics were performed in study III using binary logistic regression analyses (Osborne, 2015) to identify factors that predicted the most supportive attitudes to families. To identify RNs with the highest scores the third quartiles were used as cut-offs (Total scale ≥110, Fam-RNC ≥46, Fam-CP ≥27, Fam-B ≥18 and Fam-OR ≥16). Highest scores were coded as 1 and others as 0. Six predictor factors were entered into the logistic regression analyses. These were derived from the demographic data for RNs and were considered modifiable through targeted interventions on individual and/or organizational levels. The predictor factors were: type of workplace, postgraduate specialization, education in cardiac and/or HF nursing care, working in an HF clinic, general approach in the workplace and competence in working with families. Nagelkerke R² was used to explain the predictor factors’ contribution to the variance in the outcome, and Hosmer–Lemeshow goodness-of-fit was used to assess the fit between the model and the data. The overall significance level was set at p < .05. Statistical analyses were performed using IBM SPSS Statistics version 22.0 for Windows.

5.5 Ethical considerations

Studies I, II and IV were approved by the Regional Ethical Review Board in Uppsala [Dno. 2012/541; Dno. 2016/007]. Study III was provided with an advisory opinion from the Regional Ethical Review Board in Uppsala [Dno. 2015/014] as formal ethical approval was not required for this study. All studies conformed to the principles outlined in the Declaration of Helsinki.
Participants in the four studies received written information before consenting to participate. The information included the background and purpose of the current study, that data would be kept confidential and participants’ anonymity in data processing and presentation of results would be ensured. Participants were informed of the voluntary nature of their participation, which they could discontinue at any time without explaining why. In studies I and IV, the FCs and persons with HF were assured that, if needed, a counsellor would be available for support. In all studies, participants signed a written informed consent except in study III, where RNs could decline participation by not responding to the survey.
6 RESULTS

6.1 Family caregivers’ situation and needs – perspectives of family caregivers and registered nurses (I+II)

6.1.1 Living in a changed existence

The FCs and RNs in the first two studies acknowledged the challenges the FCs had to overcome as they lived in a new situation with substantial demands without receiving sufficient external support.

The FCs spoke of new responsibilities in their everyday life that challenged established roles in the relationship and were reported as burdensome, but were also perceived as a means for personal growth. The spousal FCs were responsible for medication regimens, all domestic care and for comforting and reassuring their near one. The FCs experienced an ever-present uncertainty caused by the unpredictable course of HF. In the event of sudden deterioration, the FCs wanted to be physically present, which restricted their possibilities to travel, work full-time and engage in personal activities outside of the home. Particularly difficult for the FCs was to witness their near one’s gradual deterioration in the absence of good days. When no longer believing in their near one’s recovery, it was challenging for them to be compassionate and encouraging, but nonetheless they continued to provide support. Although the FCs spoke of social isolation, self-sacrifice to some degree, and feelings of hopelessness and exhaustion, they also found ways to restore strength, strengthen their motivation to care and to move forward with their lives. The FCs were grateful for still having their near one by their side and perceived caregiving as a means of achieving increased closeness and solidarity with one another. In the spousal relationships, the FCs spoke of reciprocity of care in that the FC and their near one at times took turns in being the caregiver versus the caretaker. It was important for the FCs that their near one did not take the caregiving for granted but instead appreciated and understood that HF also influenced the FC’s life. (I)
The RNs perceived the FCs as the prime carriers of the medical responsibility for their near one. The FCs were considered to handle the responsibility with varying degrees of worry and uncertainty, which were perceived to also be related to the severity of their near one’s HF and their near one’s lack of adherence. The RNs in the hospitals perceived the hospitalization of the person with HF to be a temporary respite from caregiving for the FCs. The hospitalization was considered to be an eye-opener on FCs’ untenable home situation. Overall, the RNs’ descriptions of the FCs’ situation showed a strong tendency towards the negative. The RNs perceived the FCs’ situation to be burdened by feelings of guilt, duty of care, bad conscience, social isolation, being forced to ‘play the second fiddle’ and struggling without complaining. The RNs in the PHCCs perceived that the FCs toned down their description of their strenuous situation. The positive experiences of caregiving that the FCs spoke of in study I were not acknowledged by the RNs. (II)

6.1.2 Comprehension of the heart failure condition

The FCs experienced an uncertainty due to lack of knowledge on how to better handle the HF condition in order to delay deterioration. Despite lacking in knowledge, they still perceived themselves to better comprehend the HF condition than their near one did. Irritation, sadness and resignation were expressed regarding the incongruence between their own and their near one’s understanding and acceptance of the HF condition. To have HF entailed diffuse pain, fatigue, fear of being alone, feeling downhearted, loss of strength, and feelings of inadequacy and discontentment. The FCs observed these symptoms and questioned their near one’s lack of comprehension that the symptoms were illness-related. As the prognosis of HF was not easily discussed with their near one, a silent distance and frustration grew in the relationship. The FCs adjusted to being on non-speaking terms and kept their thoughts to themselves. They appreciated the health care professionals’ forthrightness about the prognosis of their near one’s HF, which could result in their near one’s acceptance of more realistic expectations and plans. (I)

The RNs in the hospitals perceived the FCs to lack knowledge and understanding of their near one’s quick deterioration in HF, while also wanting to learn how to detect early signs of deterioration in their near one’s HF to avoid rehospitalisation. There was an inter-group agreement of all
FGIs on the need for the RNs to share their knowledge of HF to improve the FCs’ ability in early detection of deterioration. In several of the RNs’ accounts, the FCs were perceived as not wanting to understand that HF was a progressive condition and steadily deteriorating process, but rather thought it was a condition that could be kept in complete control with the appropriate medication. On the other hand, the RNs did not want to deprive the FCs and the persons with HF of their hope and positive spirit and were therefore unwilling to inform the persons with HF and their FC about HF as a serious and deteriorating condition. (II)

The RNs in the hospitals perceived the relational incongruence between the FCs and their near one. It was considered to stem from lack of comprehension of the severity of HF and how to manage it, and was particularly noticeable in relation to seeking emergency care. While the FCs urged their near one to seek care, the person with HF downplayed their symptoms of deterioration, thus delaying treatment. The RNs considered the FCs’ assessment of symptoms to be the most correct. The RNs also observed FCs’ irritation with their near one’s lack of energy or even laziness, which was perceived by the RNs to demonstrate the FCs’ lack of knowledge about symptoms and medication treatment. (II)

6.1.3 Interaction between family caregivers and health care professionals
To let their near one be in focus when meeting with health care professionals was understandable and rational for the FCs, while the FCs also expressed a need to be seen and acknowledged. They had seldom been asked by health care professionals about how they were doing or asked if they needed support. Also, the FCs had not been offered information and education on the near one’s symptoms of HF, its treatment and consequences, nor was the FCs’ specific expertise requested. They expressed a need for involvement with health care professionals in their near one’s health care. Lacking this involvement caused uncertainty and feelings of exclusion for the FCs, while they also lost important information regarding their near one’s changes in medication regimens, symptoms and well-being. Lack of involvement equated to a lost opportunity to talk with health care professionals about the emotional and relational consequences of HF. (I)

All the RNs lacked a routine to invite the FCs to the visits together with the person with HF. A few of the RNs’ accounts touched upon recognizing the
specific expertise the FCs’ had of their near one, but the RNs did not acknowledge the FCs’ feelings of exclusion or need for involvement with health care professionals in their near one’s health care. The RNs in the PHCCs perceived relational incongruence when observing how the person with HF took family caregiving for granted and did not realize the long-term demands they placed on their FC. The RNs also described how the FCs never explicitly expressed their caregiver burden and need for external support when their near one was present. The FCs only hinted between the lines so as not to hurt or aggravate their near one. When alone with the RN, the FCs expressed their fatigue, need for support and a temporary respite from caregiving in order to focus on their own well-being. The RNs in the PHCCs spoke of how they wanted to improve the FCs’ situation, whether it concerned practical issues, lack of knowledge or emotional discomfort, but felt hindered in doing so due to time constraints. Instead, they avoided asking about the FCs’ situation as they could not perform appropriate nursing interventions besides referring the FCs to other professionals. (II)

Nonetheless, the FCs captured their own mandate through acting as deputies for their near one and claiming their rights of involvement in their near one’s health care. The direct access to the medical clinic was a source of relief and support for the FCs, and the open telephone line with an RN specialized in HF was greatly appreciated among those who had this contact established. The FCs took charge of their near one by seeking emergency care if they considered it necessary. They would also push their reluctant near one to bring up urgent matters with the physician. Initiatives taken by the FCs to participate in meetings with physicians and registered nurses were experienced as positively received by health care professionals. (I)

In both hospitals and PHCCs, the RNs acknowledged the importance of offering easily accessible and clear contact channels for the FCs and their near one with health care. There was an overall agreement among the RNs that the FCs preferred the continuity and security of having a permanent health care contact to call whenever needed. In the hospitals, the RN in the nurse-led HF clinics were such a permanent contact. Even though the RNs in the PHCCs lacked education in cardiac care and routines for follow-up of persons with HF, a similar system of continuity was deemed possible, but no such contact routines existed at present in the PHCCs. (II)
6.1.4 Registered nurses’ interventions to improve family caregivers’ situation

6.1.4.1 Individualized support and information (II)
The RNs perceived themselves as responsible for initiating the discussion with the FCs on emotional and practical support. The FCs were rarely inclined to do so themselves why they “needed help to ask for help”. The RNs were explicit about their responsibility to support the FCs in their quest for help but always with respect for the wishes of the person with HF.

The RNs in the hospital described themselves as advocates of self-care and considered it important to convey the information in a comprehensive way. It was their responsibility to help and guide the person with HF and their FC to find new ways to live as normally as possible. For informational purposes, the RNs encouraged joint health visits, especially at hospital discharge, but not for the benefit of the FC or the family as a unit but rather to improve the self-care of the person with HF. Adherence to self-care was believed to be higher if both parties heard and understood the reasoning behind the self-care regimen. Also, the person with HF sought health care earlier when having a well-informed and motivated FC by their side. A few RNs acknowledged that the FCs’ presence created a win-win situation as they had expert knowledge about their near one’s health status in addition to gaining important knowledge on HF and self-care. The FCs also helped the RNs to understand reasons for deterioration, as well as compensating for their near one’s eventual cognitive impairment.

6.1.4.2 Cooperation, collaboration and extended arenas for support and information (II)
Cooperation between the nurse-lead HF clinic, or medical outpatient clinic, and various other units in the hospitals was considered by the RNs in the hospitals to be satisfactory. To bypass the strenuous emergency unit care, a direct line from admission to hospital to the cardiac ward was established in one hospital. Also, the medical outpatient clinic provided diuretic intravenous treatment when symptoms of deterioration were identified early, thus again bypassing the emergency unit.

RNs in the hospitals expressed the need for improved collaboration with the PHCCs in the region, and home care and home health care in the municipality. To solve this dilemma, RNs in the hospitals suggested three interventions: to expand on the hospital-based advanced home health care
services, to develop a closer collaboration with the FCs, and to establish a coordinated individual care plan together with the municipal care as a basis for collaboration to prevent re-hospitalizations. The importance of a coordinated individual care plan on hospital discharge, as a preparation before returning home, was also emphasized by the RNs in the PHCCs.

The RNs in the hospital suggested hospital-based open lectures about HF on a regular basis as an extended arena for support and information. Another suggestion was to start support groups in the hospital or in the community, preferably in combination with education on HF. One nurse-led HF clinic had regularly booked exercise and swimming groups for persons with HF, to which the RNs suggested that the FCs could be invited. The RNs in the hospitals considered the knowledge of HF care to be inadequate among the home care personnel, the RNs in the PHCCs, and municipality’s RNs working in home health care. The RNs in the hospitals thus suggested education for all three groups, which could lead to increased support for the FCs.

RNs in the PHCCs discussed the importance of early identification of persons with HF in primary care, which could indirectly be supportive for the FCs. Two arenas for early identification were suggested: when taking the person’s blood pressure and during health screening of persons 75 years and older.

6.2 Registered nurses’ attitudes towards the importance of family involvement in heart failure nursing care (III)

6.2.1 Demographic data for registered nurses
The majority of the 303 RNs participating in the web-survey were female \((n=280; 92\%)\) and worked in a hospital setting \((n=262; 86\%)\). A total of 159 RNs \((52\%)\) had education in cardiac and/or HF nursing care and 111 RNs \((37\%)\) worked in an HF clinic.

In the demographic data with free text responses, 26 of the RNs with a general approach to the care of families in their workplace \((n=37)\), described how they invited family members and provided them with illness-related information in health visits. They also provided group education on a regular basis to persons with HF and family members and tried to be attentive to
their needs. The RNs who reported that they lacked competence in working with families \((n=114)\), were asked about the reasons behind this. A total of 64 RNs said they lacked formal education on care for families and/or lacked a shared approach to the care of families in the workplace. The RNs also described lack of time and routine as hindrances to competence development; while structured and supportive teamwork, reflective discussions and ethical guidance in complex care situations were facilitators for competence development. Lastly, 58 of the RNs who had experience of serious illness in their own family \((n=160)\) described previous, and/or present, feelings of loneliness, powerlessness and helplessness in relation to health care. Their experiences also included satisfaction with home care and basal and advanced home health care. From their own experiences, the RNs acknowledged and stressed the importance of receiving adequate information and of being offered involvement in their near one’s health care.

6.2.2 Overall attitudes towards family involvement

The median score of the total FINC-NA scale was 101 \((q1–q3 = 90–110)\), indicating that overall, the RNs’ had a supportive attitude to families’ involvement in HF nursing care. The scores had a skewed distribution. Of the instrument’s 26 items, 20 items had a median score of 4 while the remaining six items had a median score of 3. On a single-item level, there was a significant difference between the RNs’ cognition and their self-reported behaviour on the same matters. Significant differences in the demographic subgroups comparison for the four subscales of FINC-NA were found.

The median score for the subscale Fam-RNC was 41 \((q1–q3 = 37–46)\). Viewing families as a resource implies valuing families’ presence in nursing care, inviting them to take part in the care of their family member, creating a good family–nurse relationship, and seeing family members as cooperating partners. The RNs <35 years, male RNs, RNs without postgraduate specialization and RNs with 1–10 years of experience in HF nursing care had significantly less supportive attitudes.

The median score for the subscale Fam-CP was 24 \((q1–q3 = 21–27)\). Viewing families as conversational partners implies inviting families to actively take part in nursing care, discussing changes in HF condition and involving families in the planning of care. This subscale included the two items that scored the lowest of all items in FINC-NA. The RNs with no
general approach to the care of families in the workplace and RNs without competence to work with families had significantly less supportive attitudes.

The median score for the subscale Fam-B was 16 (q1–q3 = 13–18). Viewing families as a burden implies having no time to acknowledge and take care of families and considering families as undesirable in nursing care. The RNs <35 years, RNs working in hospital, RNs with ≤20 years since graduation, RNs without education in cardiac and/or HF nursing care, RNs with 1–4 years of experience in HF nursing care, RNs not working in a HF clinic and, lastly, RNs without competence in working with families had significantly less supportive attitudes (i.e., viewed families as a burden).

The median score for the subscale Fam-OR was 14 (q1–q3 = 11–16). Viewing families as its own resource implies supporting families in acknowledging and using their own resources to handle their situation. The RNs <35 years, RNs working in hospital, RNs without postgraduate specialization, RNs without education in cardiac and/or HF nursing care, RNs with 1–10 years of experience in HF nursing care, RNs not working in a HF clinic, RNs with no general approach to the care of families in the workplace, RNs without competence to work with families, and, lastly, RNs without experience of serious illness in their own family had significantly less supportive attitudes.

6.2.3 Factors predicting the most supportive attitudes

The most supportive attitudes towards families as a resource in HF nursing care are 2.53 times more likely to be held by RNs with a postgraduate specialization (district nurse specialization). The most supportive attitudes towards families as conversational partners are 2.44 times more likely among RNs with a general approach to the care of families in the workplace and 1.87 times more likely among RNs having competence to work with families. The most supportive attitudes towards not viewing families as a burden were predicted by being a RN working in a PHCC (OR=4.19), having a postgraduate specialization (district nurse specialization) (OR=2.08), having education in cardiac and/or HF nursing care (OR=2.65), working in a HF clinic (OR=2.51) and having competence to work with families (OR=1.92). The most supportive attitudes towards families as their own resource were predicted by all included factors (OR ranging between 2.31 and 3.31).
6.3 Family Health Conversations via telephone in heart failure nursing care (IV)

6.3.1 Families’ and registered nurses’ experiences
FCs reported a reduced caregiver burden in the quantitative measures after participating in the FamHCs, in particular a reduction of worry about their near one. In the joint interviews, families described how the FamHC had helped families to clarify misunderstandings about their feelings of worry. Family members did not want to cause one another worry by talking about one’s own worry about HF deterioration or prognosis. This concern for one another resulted in silence and unawareness of the other’s experiences, thoughts and beliefs. The FCs expressed that the openness and ‘permission’ to talk about one’s own irritation and worry with a third person listening was a relief and a comfort. Some FCs described a new awareness of the need to constrain their worry and uncertainty in order to limit HF’s influence on their daily life.

In the quantitative measures, both FCs and persons with HF reported higher scores for cognitive and emotional support from the RNs after the FamHCs than before. For some FCs it was the first time that they had been involved in a conversation with their near one and an RN, and in which they had a chance to express their experiences of the caregiving situation. In the joint interviews, the families conveyed how their concerns were affirmed and taken seriously by the RNs. The RN was spoken of as a ‘supportive witness’, meaning that the families felt supported when RNs listened to the families’ narratives and supported them in dealing with their experiences of, for example, worry and relational incongruence.

Before the FamHC, the FCs needed more communication with their near one, and stated that this communication was difficult to a higher degree than persons with HF did. After the FamHCs, the scores were reduced and equal on the need to communicate with one another, suggesting an improved congruence. In the joint interviews, families described how the FamHCs had contributed to a more open communication in the families. Before the FamHCs, the person with HF trivialized, or camouflaged, symptoms while the FC observed the deterioration but was unable to discuss this with their near one. Through the FamHCs, the families now spoke of an increased openness about beliefs and understanding of symptoms and also discussed new issues that they previously had been hesitant to bring up.
In the interviews with RNs, the FamHCs were described to have had an impact on RNs’ work. As the agenda for the FamHC was decided upon by the family, and not the RN, the families’ need to speak about issues beyond medication management and illness became evident to the RNs. It was at first slightly awkward for some RNs to speak openly about relational and private matters with the families, while FamHCs also painted a more complete picture of how the family situation ‘really was’. The RNs claimed that the FamHC had helped them to become more sensitive and empathic towards FCs and more interested in their caregiving experiences. For the RNs to retain a collaborative, non-hierarchical relationship between the families and themselves was at times challenging. Most challenging for the RNs was to grant equal value to all family members’ views when some of the views were in sharp contrast to the RNs’ medical knowledge of self-care management, and/or when the person with HF was considered to be in denial. Even though the RNs’ professional and personal opinions were, at times, strained in these conversations, the RNs still complied with the FamHC model’s core components and characteristics. The RNs described how their previous discomfort with silence had subsided since working with FamHCs. The RNs spoke of how silence was a powerful tool to give time for new thoughts and ideas to emerge and be voiced.

An additional category, beyond the predetermined categories, emerged when analysing the interviews. Both the families and the RNs discussed the importance of a freedom of choice regarding when to conduct FamHCs. Families and RNs were unanimous in that FamHCs should be offered to persons with HF and their family caregiver soon after HF diagnosis to early detect relational issues in the family. The FamHCs would be a suitable complement to the RNs’ routine follow-up in education on HF and self-care management. They would be also be useful and supportive after a sudden exacerbation and deterioration of HF. Families also suggested that the RNs’ routine check-ups via telephone could be in the form of a FamHC.

6.3.2 Families’ and registered nurses’ perceptions about feasibility

Overall satisfaction with FamHCs via telephone was found. For families, the positive aspects included the comfort of remaining in one’s home and the possibility for FCs who lived far away, were short of time, or were in their workplace, to still participate in a FamHC. The negative aspects were mostly
of a technical nature and included occasional line noise. Families also experienced a certain tension when there was a prolonged silence and mistook it for a shutdown telephone line. Thus the relaxed atmosphere and recurring silence, characteristics of FamHCs, were somewhat compromised via telephone. The communicative advantages of ‘in person conversations’, such as verbal nuances, facial expressions and body language, were partly lost in FamHCs conducted via telephone. In the event of strong emotional reactions in the FamHCs, the appropriateness of conducting them via telephone was questioned. Nevertheless, FamHCs via telephone were experienced by families as ‘good enough’. The increased availability of involving FCs in HF nursing care and initiating nurse-family relationships were seen as the main advantages.

The RNs preferred meeting with persons with HF and their FCs in the same room. Over the telephone, important emotional cues between the person with HF and their near one could be missed, which may have led the RNs to misinterpret the situation and the relationship between family members. Also, the inability for the RNs to see bodily reactions and looking into the eyes of the family members created an insecurity for the RNs. For these reasons, it was important for the RNs to have established a relationship with the FCs prior to the FamHCs via telephone. On the other hand, when the RNs were comfortable and had previously met both the person with HF and their FC in person, the RNs experienced a relatively greater ease when speaking about sensitive issues as the distance given by the telephone had a buffering influence. Over the telephone, the focus would be entirely on the conversation, on what was actually said and heard, without the disturbance of visual inputs or the need to perform illness-related routine checks.

RNs considered three FamHCs to be one too many. As core issues had already been discussed in the first and second FamHCs, the content of the third FamHC was experienced as repetitive. The stipulated minimum time of 30 minutes per FamHC was a reasonable time to allow for more in-depth conversation, except in the third FamHC when it was considered to be too long. The feasibility of conducting FamHCs in the RNs’ daily work was questioned due to the current length and number of FamHCs. Nevertheless, RNs saw several advantages of FamHCs in general and via telephone. FamHCs had enabled contact with FCs who did not have the opportunity to come in person due to their work or geographical dwelling, and with families in which the person with HF and/or the FC were too weak to come to the nurse-led HF clinic.
7 DISCUSSIONS

7.1 Discussion of findings
To the best of my knowledge, this thesis is the first to explore RNs’ perceptions about the situation of FCs to persons with HF, and RNs’ attitudes towards family involvement in HF nursing care on a larger scale in Sweden, and also the first to explore the Swedish practice model of FamHC in the specific area of HF nursing care. The main findings of interest in this thesis – FCs’ uncertainty, FCs’ relationship quality with their near one, and family involvement with health care professionals – are recurring concerns in all four studies and link them to each other. These findings have previously been considered from different angles in the discussion sections of the respective four papers, and will here be discussed further in relation to one another, to previous research, and to the premises of the theoretical perspectives.

7.1.1 Family caregiving – restructuring reality
The FCs in study I found themselves living in a changed existence with substantial demands on their physical and emotional health and family functioning. One of the primary burdens was the medical responsibility, medical instability of their near one’s HF and the unanticipated emergency visits to hospital, which led to FCs’ persistent worry and uncertainty. The FCs had an important medical role in strengthening self-care, monitoring symptoms and seeking medical care for their near one, while being modest about their own personal needs and in claiming their rights of support in the health care system. Additional reasons for the FCs’ uncertainty became clear, namely their lack of knowledge about the HF condition, and lack of support and involvement with health care professionals. FCs’ uncertainty has previously been discussed as characteristic of FCs to persons with HF in relation to the unpredictable trajectory of HF, their stress about what the future holds, and their lack of knowledge about the HF condition (Dionne-Odom et al., 2017; Kang et al., 2011; Wingham et al., 2015). However, this uncertainty has been considered less in relation to their lack of involvement with health care professionals, as was found in study I. Uncertainty among
the FCs in study I not only involved medical uncertainty but also relational and emotional uncertainty about how to handle their caregiving role. When the FCs experienced frustration and disbelief as their near one’s HF deteriorated, without good days in between, it was challenging for them to be compassionate and encouraging. Nonetheless, they continued to provide support without receiving external support. In a study of Sullivan and colleagues (2016), the FCs considered personal qualities such as patience, compassion, thoughtfulness and understanding to be essential requirements to fulfil a caregiving role. As the FCs in study I spoke of social isolation, and feelings of hopelessness and exhaustion, they may have been engaged in a struggle to maintain compassion for their near one. If so, and as FCs have little to no support from health care professionals in their caregiving role, this struggle presumably put them at risk of negative caregiver outcomes and placed a considerable strain on the relationship with their near one.

Despite their difficult circumstances and their persistent uncertainty, the FCs found ways to restore their strength, improve their motivation to care, and move forward with their lives. The FCs’ altered role and responsibilities provided them with new self-confidence and the ability to restructure their life to achieve an acceptable normalcy, although not the same as before their near one fell ill with HF. As the literature also reports on positive aspects of caregiving (Buck et al., 2015; Clark et al., 2014; Dionne-Odom et al., 2017; Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011; Whittingham et al., 2013; Wingham et al., 2015) it is intriguing to ponder over the underlying mechanisms of the positive responses to caregiving. In study I, the positive experiences were primarily connected to a congruence in the relation with their near one. Their mutual communication and solidarity with one another improved through the caregiving, provided that the person with HF did not take the FCs’ caregiving for granted but instead appreciated it. FCs in spousal relationships also spoke of a partnership of reciprocity of care when both parties, in times of need, took turns in being the caregiver versus the caretaker. This reciprocity facilitated an understanding of the other’s perspective, which also increased their empathy for one another and their mutual will to care.

Caregiving in the absence of positive relational aspects has been shown to lead to increased caregiver burden and poorer outcomes in health and well-being for both FCs and for the persons with HF (Hooker, Grigsby, Riegel, & Bekelman, 2015; Lum et al., 2014; Strömberg, 2013). In study I, the FCs were negatively affected by the relational incongruence with their near on
the comprehension of self-care, symptoms and prognosis of the HF condition. When the person with HF had not accepted their HF diagnosis and was unwilling to discuss the distress HF caused, the FCs’ feelings of hopelessness and frustration increased. The FCs felt emotionally isolated in their relationship due to the lack of communication. In search of an explication of the complexity of the FCs’ role and responsibility in relation to their near one found in study I, we can turn to previous research on relationship incongruence in the area of HF. Buck, Kitko and Hupcey (2013) point towards the several different dyadic HF care types that exist. Of these dyads, Buck and colleagues (2013) showed that more than half are incongruent in reporting how they chose to manage HF. Furthermore, this relational incongruence is found to lead to more conflict and psychosocial stress and tension in the relationship (Kitko et al., 2015; Retrum et al., 2013). In the study of Wingham, Harding, Britten and Dalal (2014) persons with HF responded in a multitude of ways to their HF condition, and the FCs were affected by their near one’s responses (Wingham et al., 2015). Spaling, Currie, Strachan, Harkness and Clark (2015) found that the persons with HF claimed to ‘know’ about self-care recommendations, while also reporting an inability regarding ‘how’ to apply this knowledge in their daily lives. Their management of HF was based on how they ‘feel' rather than clinical indicators of worsening symptoms, which is in line with the findings of Gravely-Witte, Jurgens, Tamim and Grace (2010), where persons with HF were often found to delay in seeking medical treatment. Relational incongruence on the comprehension of self-care, symptoms and prognosis of the HF condition thus seems to be an essential factor for health care professionals to acknowledge and account for in order to achieve successful HF management.

The FCs’ experiences of uncertainty and incongruence in the relationship with their near one in study I were perceived as burdensome by the RNs in study II, while the FCs’ need for involvement with health care professionals in the planning and implementation of their near one’s health care was not acknowledged. Increased involvement may well have mitigated the FCs’ uncertainty and softened the relational incongruence, yet they received no support from the RNs. Instead, the FCs experienced that the health care professionals took family caregiving for granted, without supplying the FCs with appropriate tools and support, which gave rise to feelings of exclusion and had a negative influence on the relationship with their near one. In study II, the RNs did not at all reflect on the need for, or benefit of, the FCs’
involvement in nursing care. When directly asked about it in study III, less supportive attitudes towards family involvement were held by RNs who were young, male, worked in hospitals, were without postgraduate specialization, without education in cardiac and/or HF nursing care, with no general approach to the care of families in the workplace, without competence to work with families, and lastly, without experience of serious illness in their own family. In addition to having an overall less supportive attitude, male RNs had significantly less supportive attitudes towards families as a resource in nursing, which was also found by Benzein and colleagues (2008) and Åstedt-Kurki, Paavilainen, Tammentie and Paunonen-Ilmonen (2001). More research is needed to investigate why these gender differences exist. Most importantly, RNs’ least supportive attitudes were held towards families as conversational partners, meaning RNs’ attitudes towards inviting families to actively take part in nursing care, discussing changes in HF condition and involving families in the planning of care. These attitudes were held by RNs with no general approach to the care of families in the workplace and RNs without competence to work with families.

As there is a paucity of HF literature on RNs’ perceptions about the FCs’ situation and RNs’ attitudes towards family involvement, comparable literature in other nursing areas was sought to reflect my findings from studies II and III. Earlier research in hospital settings (Åstedt-Kurki et al., 2001; Laitinen-Junkkari, Meriläinen, & Sinkkonen, 2001), nursing homes (Bauer & Nay, 2003) and home care (Benzein, Johansson, & Saveman, 2004) has shown that genuine family involvement in nursing care is far from a matter of course. The RNs’ significantly less supportive attitudes towards families as conversational partners in study III, can be seen as demonstrating RNs’ intention to maintain a superficial and formal level of relationship. The reasons behind this intention are discussed by Bauer and Nay (2003) who find they lie in RNs’ uncertainties about the allocation of powers and responsibilities between the RNs and the families. This uncertainty may well have existed for those RNs in study III as they lacked a general approach towards families in their workplace and lacked competence to work with families. In study II, the RNs perceived the FCs’ role as a source of emotional and psychosocial support to the person with HF, a role recognized by RNs in general (Weman & Fagerberg, 2006). Despite being aware of FCs’ caregiver burden, RNs were not interested in how FCs managed their situation, as was also found by Åstedt-Kurki and colleagues (2001).
Salin, Kaunonen and Åstedt-Kurki (2013) found that RNs felt helpless when meeting with demanding FCs and had no other way of handling the situation than avoiding them. Perhaps, not acknowledging families’ needs of support and involvement in study II was a way of avoiding families who may otherwise have become a burden to the RNs. Similar results were found by Benzein et al. (2004) among district nurses in home care in relation to FCs that was considered demanding or who openly voiced their suffering. Managerial support and support from colleagues in facing unfamiliar and difficult situations together is the professional way of dealing with such problems, which would benefit both RNs and families.

The findings can be further understood in the context of systems theory (Öquist, 2013), IBM (Wright & Bell, 2009) and salutogenes (Antonovsky, 1987). The term ‘belief’ is not always used explicitly in the studies, but can be synonymous with attitudes, assumptions, values and meanings (Wright & Bell, 2009), as well as perceptions. Some suggest that beliefs, attitudes and values are interrelated but not the same (Benzein et al., 2004). One of the premises of IBM is that our beliefs emerge, develop and change through our interactions with others through reflection and communication. Thus, the diverging beliefs between FCs, their near one and RNs need not be static. Rather, RNs have a unique opportunity to influence their nurse-family relationship and the family’s constraining beliefs so that they become more facilitating, and thus reduce the family’s suffering (Benzein & Saveman, 2008).

Families in the midst of chronic illness may create an unhelpful or even a suffering belief due to the illness. FCs’ experiences of an ever-present uncertainty was expressed as caused by the unpredictable trajectory of HF, limited knowledge of HF and need for involvement with health care professionals in their near one’s health care. Undoubtedly, the responsibility and support from health care professionals in chronic illness should be maintained while simultaneously acknowledging yet another reason for uncertainty, namely a possible dominating belief in the family of “illness as a threat to life” as opposed to “illness as a part of life” (Walsh, 2016). If the FCs, and the family as a whole, primarily lives within the present moment, even with the experience of serious illness, and accepting “what is now” rather than focusing on the past or future and continuously challenge the present, the suffering is likely to decrease (Wright, 2015). The beliefs that the family choose to embrace are the most powerful ones, whether they may be beliefs of hopefulness and healing or unhelpful, constraining beliefs about
the cause and/or impact of the illness (Wright & Bell, 2009; Wright & Leahey, 2013). Eckhart Tolle (Wright, 2015) offers a few examples of beliefs that focus on the past or the future and invariably invite suffering: “If only I had not been so stressed with my work, this heart attack would not have happened”, “How will I be able to care for my mother at home?”, “How is he going to be able to work now with this disability?” If action needs to be taken in managing the illness, the idea or inspiration for solutions will more easily emerge from a peaceful state rather than one of suffering and anxiety (Wright, 2015). Several of the FCs in study I had a distinct focus on the past when feeling resentment toward health care professionals and when holding their near one responsible for delaying treatment and thus worsening the HF prognosis.

Using the IBM in FamHCs is one way to ease the family’s suffering since it involves acknowledging and strengthening the family’s facilitating illness beliefs and exploring and challenging the family’s constraining beliefs (Ånestedt, Benzein, & Persson, 2015; Östlund et al., 2016). To acknowledge the person with HF and their FC as a unit, as a system, is to acknowledge that when someone in the family contributes to positive and facilitating influences and beliefs, they will affect the family in a positive way, just as the illness of one family member can affect the entire family negatively (Benzein et al., 2008). The family’s experiences and beliefs should not only be considered in isolation, but also in relation to health care professionals. The RN is also part of a unit, a system, together with the person with HF and their FC, since all influence each other. Furthermore, it is not only family members that hold facilitating or constraining beliefs about illness and health, so do health care professionals, as was found in studies II-IV. RNs held beliefs about the FCs having a burdensome situation, lacking HF knowledge, being resources for informational purposes but not as partners for communication. Bell (2013) describes how the relationships between families and RNs are shaped by the beliefs of the RNs. If RNs believe that they have more education and expertise (therefore being more ‘right’) they may be less interested in inquiring about or valuing the preferences of families, or entering into collaborative relationships with them. Holding a belief that “I have no time to involve families” can constrain the relationships and conversations with families. This belief is the very opposite of the one needed when supporting and involving families in nursing care. If RNs believe “I have confidence in my knowledge and skills about how to talk to families” perhaps they would be more confident in welcoming,
including, and acknowledging families as partners. These beliefs presumably not only impact their relationship with the family, but ultimately their clinical practice as regards whether to involve families in nursing care or not (Bell, 2013).

The divergence between the FCs’ experiences and needs in study I and the RNs’ perceptions about the FCs’ situation and RNs’ attitudes towards family involvement in study II and III is important. Differences in beliefs between the family and health care professionals can result in divergent goals, unclear communication and interactional problems in nurse-family relationships (Friedman, Bowden, & Jones, 2003). FCs who experience high-quality relationships with RNs are less likely to experience feelings of isolation, vulnerability or uncertainty in their caregiving role (Wright & Bell, 2009). Furthermore, when the needs of families are addressed and their suffering is acknowledged, the time for care is optimized (Wright & Leahey, 2013), which ought to be of considerable value for RNs in their profession where time constraints in clinical practice are of great concern. As RNs frequently meet FCs to a person with HF in various health care settings and have a key role in meeting the needs of FCs, it seems essential to acknowledge and address the relationship quality not only within the family but also in the nurse-family relationship.

7.1.2 Introducing and sustaining a family-centred nursing approach in heart failure nursing care
As there are only very few FSN/family-centred nursing interventions in HF nursing care internationally (Duhamel & Talbot, 2004; Duhamel et al., 2007; Voltelen et al., 2016), the empirical research evidence on family nursing interventions in HF nursing care needs to be considerably strengthened if a relationship-focused and family-centred nursing approach is to be achieved in HF clinical practice. There is a strong research priority to investigate caregiver involvement in intervention development in HF care (Evangelista et al., 2016) and an increasing interest in the HF literature in elucidating mechanisms behind relationship quality, communication and reciprocity between FCs and their near one (Buck et al., 2013; Retrum et al., 2013).

The RNs in study II encouraged joint health visits in the hospital, especially at hospital discharge, but not for the benefit of the FC or the family as a unit, but rather to improve on the self-care of the person with HF. This is in line
with other HF nursing interventions despite the emphasis in research that nursing interventions should recognize the importance of family relationships to achieve optimal outcomes (Dionne-Odom et al., 2017; Sebern & Woda, 2012). It is also argued that family-centred nursing should be an integral part of RNs’ work, especially when caring for persons with severe and long-term medical conditions and their FCs (Benzein et al., 2008; Wright & Leahey, 2013).

The RNs in study II seemingly did not possess the tools to reduce the family’s suffering, FCs’ uncertainty and the incongruence in the relationship. In study IV, the FamHC was shown to be such a tool for RNs. In the FamHCs, the RNs experienced a process of skill improvement. They learned to patiently listen to the families and experienced an improved understanding of their situation. RNs also realized the power of silence, which gave the RNs and the families time to process and reflect on what had just been said, as well as time for new thoughts to emerge, as also experienced by RNs in the study by Dorell, Östlund and colleagues (2016). In the FamHCs, RNs became aware of their own constraining beliefs towards granting equal value to all family members’ narratives and beliefs, as some of these were challenging the RNs’ medical knowledge. Instead of the RNs’ ‘usual monologue’ aiming to rectify family members’ eventual misconceptions about self-care or monitoring of symptoms, the RNs developed an atmosphere of trust with the families and explored families’ experiences and beliefs without interrupting, questioning or judging them.

The families experienced an improved communication within the family, and increased support from RNs after the FamHCs in study IV. This improvement may have been due to the trusting environment in the FamHCs, in which all dared to express themselves and multiple realities were accepted, as also previously found in the studies of Dorell, Bäckström and colleagues (2016) and Sundin and colleagues (2016). In contrast to previous studies exploring FamHCs, the families’ in the present study did not experience a changed outlook on the future after the FamHCs. Persson and Benzein (2014) have explained the participation in FamHCs as a spiral movement towards family health. Through verbal interaction, the self and identity within the family is created, and an understanding of ways of being and interacting will emerge. In interpreting the present study’s results in the light of this spiral movement towards family health, the reduction of worry and improved communication within the family started a process that may
have facilitated changes in their ways of thinking and leading the families to eventually see the future with increased confidence.

Regrettably, despite several beneficial effects of supporting and involving FCs in nursing care, and a continuous growth in the scope and sophistication over the past 20 years of FSN knowledge, the utilization of this knowledge in RNs’ clinical practice is still on a modest level. There is a gap between what we know, and whether and how this knowledge is applied in practice with families, which is why scholars are now shifting their emphasis towards examining how FSN knowledge is translated to health care clinical environments (Duhamel, 2010; Leahey & Svavarsdottir, 2009). Bell (2014) describes how the ‘usual health care’ often does not routinely include families or acknowledge family experiences and preferences or inquire about illness suffering. This gap between knowledge and practice, and the difficulties of implementing family-centred nursing are described by several researchers in the area of FSN as multifactorial on both organizational and individual levels (Bell, 2013; Benzein et al., 2008; Duhamel, 2010; Duhamel et al., 2007; Duhamel, Dupuis, Turcotte, Martinez, & Goudreau, 2015; Saveman, 2010; Voltelen et al., 2016; Wright & Bell, 2009; Wright & Leahey, 2013).

Challenges on an organizational level are attributed to a range of factors in clinical settings, including poor managerial support, the way in which FSN is introduced, and whether health care personnel have a shared approach towards families in their workplace. For example, in study III, overall, RNs were supportive of families’ involvement on a cognitive level but not on a behavioral level (i.e., self-reported behavior), which is in line with previous findings (Caty, Larocque, & Koren, 2001; Luttik et al., 2016). The reasons behind the discrepancy between cognition and behavior may be organizational constraints that prevent RNs from involving families in their clinical practice. To overcome these challenges, family nursing implementation research agrees on the value of managerial support, which has been shown to influence decisions on striving to uphold a family approach and the distribution of educational resources in the workplace. Consequently, the question of FamHCs’ sustainability in the clinical setting is also of paramount importance. Interventions may be successful while the studies are ongoing but in order to integrate FamHCs in RNs’ daily practice on a long-term basis, the needs and demands of RNs and their workplaces have to be considered. Further studies on the organizational and financial
requisites and consequences of implementing FamHCs in heart failure nursing care are thus warranted.

Challenges on an individual level include RNs’ young age, gender, short nursing experience, level of education and their attitudes towards family involvement; the latter explored in study III. RNs’ failure to acknowledge FCs’ need for support and involvement (II) and RNs’ less supportive attitudes (III) may be a result of externalizing the ‘problem’, instead of internalizing it and embracing one’s nursing responsibility. One can also question whether RNs are aware of and understand their own importance in relation to families who are living with a severe chronic illness such as HF. The major challenges found in using a family-centred approach are the absence of role models and lack of coaching in family nursing in the workplace, together with RNs’ low level of confidence in their competence to work with families (Duhamel et al., 2015; Voltelen et al., 2016). Fortunately, the more RNs apply their family nursing training, the more they tend to acknowledge the usefulness and reward of family nursing, which enhances their confidence in their competence (Duhamel et al., 2015).

Study III identified several factors on both organizational and individual levels that may prove to be the most favourable requisites for implementing a more family-centred approach in HF nursing care. These were the factors that predicted RNs’ most supportive attitudes towards family involvement – RNs working in PHCCs or in nurse-led HF clinics, and RNs who had district nurse specialization or education in cardiac and/or HF nursing care. Besides valuing and strengthening these factors in the clinical setting and encouraging these RNs to act as role models and mentors for their younger and less experienced colleagues, there is also a need to promote a form of family-centred approach that is attractive to RNs on a long-term basis. Offering the FamHCs via telephone in study IV was an attempt to bypass the difficulties for RNs and families of leaving their workplace and/or home. Overall, families and RNs had positive experiences of FamHCs via telephone as they facilitated communication within the family and initiated and strengthened nurse-family relationships, even though the advantages of seeing and ‘reading’ one another’s emotional cues were partly lost. Previous support and coaching programs for FCs via telephone have shown positive effects on their near one’s rehospitalizations, HF management and caregiver outcomes (Piamjariyakul et al., 2013, 2015; Piette et al., 2015), however these interventions primarily concerned self-care, and not beliefs and family relationships. It is therefore encouraging that Chiang et al. (2012) found
significant improvement of family functioning after a relationship-focused telehealth care intervention. In study IV, the advantages of FamHCs via telephone seemed to outweigh the disadvantages for both families and RNs. To avoid misinterpreting the situation due to not seeing each other the technology of Skype can be used, or other online devices as shown in a study by Lindh and colleagues (2013).

The RNs in study IV preferred to conduct only two FamHCs with a maximum length of 30 minutes. Bell (2012) discusses how the brief 15-Minute Family Interview has proven to be the most attractive and feasible of the practice models in FSN and is easily translatable to clinical settings. Four hours of teaching sessions and training has been shown to suffice in order to prepare RNs to conduct the 15-Minute Family Interview. There are several successful and sustainable examples of integrating the 15-Minute Family Interview in RNs’ daily clinical practice (Braun & Foster, 2011; Martinez et al., 2007; Svavarsdottir, 2008; Svavarsdottir et al., 2012). Leahey and Wright (2016) discuss how a majority of young and inexperienced RNs feel insecure and anxious about meeting with families and will mask their apprehensions by stating shortage of time as an argument against involving families in their nursing practice. However, once RNs embrace the belief that “illness is a family affair” (Wright & Bell, 2009) and understand that they can make a profound difference to reduce suffering in only 15 minutes or less, they challenge their constraining belief of not having enough time. It should be noted though that a certain amount of tension exists in the literature on whether or not family nursing should be limited to RNs with advanced education (Braun & Foster, 2011). Duhamel and colleagues (2007) and Voltelen and colleagues (2016) underscore in their studies that in addition to being an experienced RN who feels secure in one’s own professional capacity, it is important for RNs to acquire expert knowledge in HF and nursing skills in family nursing in order to work successfully with families. A shorter version of the tested FamHCs within family-centred nursing is presumably manageable. In the area of HF nursing care, a shorter version of the FamHC would be feasible in health units where RNs have a designated consultation time with persons with HF and their FCs, as in a nurse-led HF clinic in a hospital or PHCC. A short FamHC can also be feasible in all encounters with families struggling with HF, whether they take place in a hospital ward, in a regular blood pressure check-up in the PHCC, in home health care or in a telephone call.
7.2 Methodological considerations

7.2.1 Trustworthiness in a qualitative inquiry (I+II+IV)

The concept of trustworthiness was developed by Lincoln and Guba (1985) to fit the assumption of qualitative inquiry and was adopted across a range of disciplines and traditions. Trustworthiness includes the five criteria of credibility, dependability, confirmability, transferability and authenticity (Lincoln & Guba, 1985, 1986; Polit & Beck, 2014). Of relevance for the trustworthiness of this thesis, the following section discusses the appliance of credibility, dependability and transferability, in relation to the theoretical and practical challenges encountered during the data collection and data analysis in studies I, II and IV.

7.2.1.1 Credibility

Credibility refers to confidence in the truth value of the data and interpretations of them. Credibility involves two aspects: conducting the study in a way that enhances the believability of the findings and taking steps to demonstrate credibility to readers (Polit & Beck, 2014). In studies I and II the respective aims were to explore the FCs’ experiences and needs, and RNs’ perceptions, with an open mind towards what would be found, which was why an inductive approach was most appropriate (Hsieh & Shannon, 2005; Polit & Beck, 2014). In study IV, the aim was to explore families’ and RNs’ experiences of the already existing model of FamHC but used in a different context (i.e., HF care and by use of a telephone), which is why a deductive approach was chosen (Hsieh & Shannon, 2005; Polit & Beck, 2014). The data in study IV was thus viewed in a specific way, like looking through a lens, searching for specific issues or categories related to the theory and model in use.

Individual interviews in study I were considered most appropriate when discussing private, relational and perhaps sensitive issues of the FCs’ experiences and needs (Kvale & Brinkmann, 2009). A limitation was that only a third of the FCs who were contacted, agreed to participate in the study. Two of the three reasons given for non-participation, being short of time and experiencing their own ill health, may indicate a more demanding care situation and thus the study may underestimate the need of support. The third reason, which was not having anything useful to contribute, may have been an expression of how they undervalued their role as FCs or were not aware of their needs. The point at which saturation of data is reached is
difficult to identify. New data may always add something new, but with diminishing returns, and the cut-off point between adding to emerging findings and not adding might be considered arbitrary (Mason, 2010). Nevertheless, the sample of 14 interviews was sufficient to provide a variety and depth of experiences and enable development of meaningful themes and useful interpretations (Morse, 2000). The location for the interview was decided upon by the participants to optimize their feeling of security and control during the interview.

In study II, FGIs were chosen for data collection in order to benefit from their quality in facilitating richness in associations of the participants’ experiences (Barbour, 2007; Krueger & Casey, 2015). FGIs offer opportunities of multiple interactions; between the moderator and participants and also among the participants in the focus group. Participants may engage in the interview assuming an informal role as ‘co-moderators’ and even ‘co-analysts’, asking helpful questions to one another, formulate explanations and ‘theorize’ own and others’ responses (Barbour, 2007). An alternative method for data collection is individual interviews, which might have given deeper knowledge about the phenomena in question as FGIs may inhibit participants from sharing their perceptions in a group, thus affecting credibility. However, participants in the respective focus group were all RNs and colleagues in the same workplace, thus they shared the same specialty, there was educational homogeneity, and they were comfortable around each other. All RNs in the FGIs had a high level of interaction in the process of comparing and contrasting views, and constructing meaning about the topic for the interviews.

Intra-group agreement was high in all interviews. Intra-group agreement can perhaps camouflage power play between participants and there is always a risk in FGIs that some participants’ voices are drowned out by others. This risk was not observed by the moderator or co-moderator; instead some participants were more verbal and, seemingly with the others’ consent, had a greater ability to summarize what several other participants tried to express, but in a more straightforward way. Interaction in a group is believed to stimulate thoughts and feelings of participants who may feel that they otherwise have little to contribute in a research project or who are reluctant to elaborate on their perspective or thoughts in a one-to-one interview (Barbour, 2007; Holloway & Wheeler, 2010). As only a minority of the participating RNs had previously reflected on the situation of FCs, the focus group format turned out to be particularly suitable in this study as the group
dynamic assisted the participants to actively clarify their views, which presumably compensated for the more in-depth knowledge eventually gained in individual interviews. Lastly, the RNs in study II did not have first-hand experience of the topic for the interviews; instead, they contributed with their perceptions about the situation of others. This ‘meta-level’ perspective calls for caution in relation to credibility.

The number of FGIs, and the composition and size of each FGI are topics of debate among researchers. McLafferty (2004) recommends intra-group homogeneity as it improves group dynamics and interaction. Morgan (1997) recommends the composition of homogenous groups only in terms of background but not attitudes, while others view differences of opinion as potentially disruptive. Compatibility between participants can be more productive than conflict or polarisation, yet conflict can generate new and different ideas (Holloway & Wheeler, 2010). In study II, intra-group homogeneity was deliberate in terms of working place, and was used to explore an inter-group comparison between hospitals and PHCCs (Barbour, 2007). The homogeneity may also have been a limitation as the RNs in one health unit missed the opportunity to share, discuss and understand the perceptions and feasible interventions of RNs from another health unit in the health organization. On the other hand, the RNs in PHCCs may then have been inhibited in the FGIs by the hospital RNs’ relatively greater expertise and daily experience in HF nursing.

As to the question of how many FGIs to conduct, this is determined by the desired amount of comparison. Two groups with participants with similar characteristics is considered sufficient (Barbour, 2007), although others recommend three or four groups if there is intra-group homogeneity (Holloway & Wheeler, 2010; Krueger & Casey, 2015). In study II, three FGIs with intra-group homogeneity in hospitals and three FGIs with intra-group homogeneity in PHCCs were conducted. The recommended number of participants in each FGI also shows variation (Barbour, 2007; Holloway & Wheeler, 2010). Six participants is probably an optimum number as it is large enough to provide a variety of perspectives and small enough not to become disorderly and fragmented (Holloway & Wheeler, 2010). FGIs with three-four participants are judged to be optimal by some researchers and even preferable when exploring in-depth meanings (Barbour & Kitzinger, 1999). In a small FGI, there is more time for each participant to express their opinion, ask questions, and interact and respond to other participants’ responses, which was the case in study II with three to five participants in
each FGI. The flexible choice of location, being the RNs’ respective workplaces, was a strength as it maximized the RNs’ possibilities to participate.

Joint interviews were chosen to explore families’ experiences of FamHCs in study IV. Joint interviews were considered more appropriate than individual ones, in order to proceed with the family approach initiated in the intervention. Joint interviews combine some of the advantages of FGIs, such as the opportunity for participants to support and prompt each other, while reducing some of the drawbacks, such as the limited access offered by larger groups to detailed narratives from each participant (Morris, 2001). Access to the interaction between the two participants is a central feature of joint interviewing and also the main advantage over individual interviews. The advantages include the opportunity to study the interaction itself and to obtain data that are generated by this interaction. One of the most fruitful kinds of data from joint interviews is provided when the two participants contradict each other, particularly where contradictory claims are negotiated in relation to shared experiences (Polak & Green, 2016). Torgé (2013) suggests that joint interviews provide access to ‘we-talk’ in which the participants discursively co-produce themselves as a couple working together to deal with shared problems. The disadvantages are that the joint interview may silence an individual’s account, particularly when talking about sensitive topics, or when wanting to protect one another from worries (Polak & Green, 2016). These disadvantages were not considered as ethical challenges in study IV as the participants had already had three FamHCs prior to the joint interviews, in which sensitive topics and disclosure of participant’s private accounts had been made. Also, the exploration in the joint interviews did not concern the families’ experiences about their relationships and life together; instead, the aim was at first hand to explore the families’ experiences of the FamHCs as an intervention, and secondly to explore if it had brought any change into the families’ lives. In the joint interviews the participants performed some useful interactive work, in prompting and clarifying each other’s assumptions and tacit knowledge.

One of the aspects of credibility is reflexivity, or researcher credibility and pre-understanding. It refers to acknowledging the ways in which the researcher actively contributes to the data generated, at every step of the research process. In this thesis, I brought life experience as an RN, and living with persons with HF, into the research process. This experience and this set of values may have helped me to better understand the context within
which the FCs lived and RNs worked, but it also introduced a risk of researcher bias. The researcher as ‘the instrument’ calls for attention to biases, which become problematic if the researcher is oblivious to them (Barbour, 2007; Malterud, 2001; Polit & Beck, 2014). In this thesis, I both collected the data and performed the main analysis of data, which adds to the researcher bias. I may have overemphasized some participants’ accounts, and co-constructed meaning in relation to those accounts that were congruent with my own feelings and perceptions. On the other hand, an assistant moderator in the FGIs in study II helped me to reflect on and recapture the points of particular interest after each interview. Also, in all of the qualitative studies, all members of the research group verified the transcripts from all interviews, read the material, and regularly discussed alternative interpretations of the data until a consensus was reached. Another strength from a researcher credibility aspect is my previous experience of conducting and analysing interviews, and the keeping of a log book of reflective thoughts and feelings during the research process. In relation to FCs and the persons with HF, it was essential to acknowledge that as a health researcher, by virtue of my professional expertise and skill in interviewing, I was in a position of power, despite trying to achieve a relationship of equality (Holloway & Wheeler, 2010). A strength of the studies is the attempt to achieve an elaborate description of sampling, data analysis and interview extracts in the presentation of the results, which gives the reader the opportunity to assess the credibility.

7.2.1.2 Dependability
Dependability refers to the consistency and stability of data over time and in different conditions, meaning the degree to which data change over time and alterations made by the researchers during the analysis process. Dependability is closely intertwined with credibility, which cannot be attained in the absence of dependability (Polit & Beck, 2014). In studies I, II and IV, semi-structured interview guides were used with key questions in the areas of interest and follow-up questions. The semi-structured interview guide allowed the participants to talk freely about their experiences while retaining focus on the topic to be covered and the lines of inquiry to be followed. While the sequencing of questions differed between interviews as it depended on the process of the interview and the responses of each individual, the same questions were put to all participants (Holloway & Wheeler, 2010). The combination of flexibility and focus is one of the strengths of the semi-structured interview from a dependability aspect.
Another strength was the transparency in the presentations in the respective papers of both the questions in the pre-written semi-structured interview guides and the follow-up questions. All interviews were performed by the same person, which can be considered a weakness from a dependability aspect, although methodological trustworthiness was ensured by immediately transcribing the interviews and writing memos throughout the data collection and data analysis process. I performed the posttest interviews in study IV, which may have introduced a social desirability bias. On the other hand, I had a discrete role during the intervention and the results are in line with others’ evaluating FamHCs. Neither families nor RNs appeared hesitant to convey their negative experiences of the FamHCs.

In study II, space triangulation was performed as data were collected in multiple sites to test for cross-site consistency (Polit & Beck, 2014). In the analysis of the interviews, investigator triangulation was used as the entire research group verified the transcripts of the interviews and were involved in coding and interpretation of the material thus reducing the risk of biased decisions and interpretations.

7.2.1.3 Transferability
Transferability refers to the extent to which the findings can be transferred to other settings or groups beyond the context in which the study is done (Lincoln & Guba, 1985; Malterud, 2001). To facilitate transferability, it is valuable to give a clear and distinct description of the context and characteristics of participants, data collection and process of analysis. A rich presentation of the findings, together with appropriate quotations will also enhance transferability (Graneheim & Lundman, 2004). A limitation of study I was the inclusion and exclusion criteria, as FCs with dementia were excluded from the study because they were considered to be unable to express thoughtful insight into their experiences and needs. Persons with HF and dementia were also excluded to avoid comorbidity as a confounder regarding the FCs’ experiences and needs; a reason which is considered a strength. An additional limitation was that only Swedish-speaking FCs were included in the study. These criteria thus limit the transferability of the results to the population with dementia and non-Swedish-speaking populations. The underrepresentation of male FCs in studies I and IV compromises the transferability but can also be understood as a reflection of reality as the FCs who provide the most comprehensive caregiving for a near one are women (Sand, 2014). Furthermore, conclusions drawn from study I
and IV may only be transferable to other settings, situations and persons with comparable socioeconomic status and ethnicity.

RNs’ discontentment in the PHCCs in study II with the recent shift of responsibility for home health care from regions to the municipalities is highly specific to the study setting. The transferability of study II’s results should be interpreted with two different levels of RNs’ perceptions in mind. On the organisational level, RNs’ perceptions about the financial and responsibility dilemma between the region and the municipality are highly specific to the study setting. RNs’ perceptions about FCs and persons with HF are on an interpersonal level, and are more likely to be transferable to other illness groups and a variety of health care organisations.

A limitation in transferability in study IV may be that only one FC was included in the FamHCS instead of several family members. It was due to convenience reasons as increased disturbances in the conversations via telephone were anticipated if more than three persons were present. In study IV, the RNs’ and families’ perceptions and experiences may have relevance for RNs and families in similar contexts, both within HF nursing care, general nursing care and municipal elder care.

7.2.2 Rigour in a quantitative inquiry (III+IV)

The concept of rigour has its origins in science and has connotations to objectivity and measurements; hence, it has an appropriate place in quantitative research. The following section discusses the appliance of validity and reliability to achieve rigour in studies III and IV in relation to the theoretical and practical challenges encountered when conducting the intervention, data collection and data analysis.

7.2.2.1 Validity and reliability

Validity is defined as the extent to which a concept is accurately measured in a quantitative study. Reliability refers to the consistency of the research instrument. It is also linked to replicability, meaning the extent to which the instrument consistently produces the same results when used in similar circumstances and conditions (Heale & Twycross, 2015; Polit & Beck, 2014).

One of the threats to statistical conclusion validity is low statistical power due to a small sample size, or the alpha value being set low, which increases
the likelihood of making a Type II error (i.e., accepting a false non-significance when in fact there is a difference between groups). The other threat is the fishing and error rate problem. When performing numerous statistical tests the likelihood of making a Type I error increases (i.e., accepting a false significance when in fact there is no difference between groups) (Moore, McCabe, & Craig, 2012; Polit & Beck, 2014). In study III, a power analysis estimated the needed sample size prior to sampling. The sample size of 303 RNs completing the FINC-NA was considered more than satisfactory. The alpha value was also set to the standard of 5%. Another threat deals with reliability of measures. Cronbach’s alpha (Moore et al., 2012; Polit & Beck, 2014) is the most commonly used test to determine the internal consistency of an instrument and was the measure used in study III. The Cronbach’s alpha result is a number between 0 and 1. An acceptable reliability score is one that is 0.7 or higher (Streiner & Norman, 2008). The FINC-NA (III) had satisfactory internal consistency by Cronbach’s alpha of 0.86 for the Total scale, 0.87 for Fam-RNC, 0.79 for Fam-CP, 0.71 for Fam-B and 0.79 for Fam-OR.

Threats to internal validity relevant for study III are selection bias due to response rate and response bias. Selection bias is a systematic difference between groups (Moore et al., 2012; Polit & Beck, 2014). A convenience sampling was done with broad eligibility criteria of RNs. Although the response rate of 59% was satisfactory in a study with a web-survey design, I had no control or knowledge about whether there was a selection bias between the RNs that responded and those who did not. I only became knowledgeable about the non-response rate of the RNs and health care unit and plausible explanations. Of the eligible 111 PHCCs, only 30 were included in the study. Explanations for this were that managers in PHCCs responded with contact information of the RNs to a lesser degree than did managers in hospitals, and the RNs in the PHCCs did not meet persons with HF although physicians reported data to The Swedish Heart Failure Registry. Also, PHCCs did not have a nurse-led HF clinic and proportionally fewer RNs per PHCC that represented each PHCC in comparison with the RNs in hospital. Regarding individual RN’s reasons for non-response it is possible only to speculate, but reasons may include time constraints, high workload, lack of interest in the research question, length of the questionnaire and being uncomfortable with the web-survey design. Thus, generalizing the findings to the total population of RNs in HF care should be done with caution without replicating the study with another sample.
Threats to construct validity concern the degree to which an instrument (III, IV) and/or an intervention (IV) measure the phenomena it/they were intended to measure (Moore et al., 2012; Polit & Beck, 2014). In study III, it was considered a strength to use the highly valid and reliable FINC-NA instrument, developed and tested in a Swedish context (Saveman et al., 2011). Researchers who have previously used the FINC-NA have come to similar outcomes as the ones found in study III, which suggest a satisfactory degree of construct validity. In study IV, intervention fidelity, which is the extent to which the implementation of a treatment is faithful to its plan, was central. To enhance construct validity it was thus important to find and use valid measures to assess and ensure RNs’ fidelity to the core components of FamHCs (Östlund et al., 2015). Thus, I listened to each RN’s first and third FamHC with each family. Immediately after concluding the first FamHC, the RN and I discussed the process and fidelity to the core components of the recently performed FamHC, and the RN was provided with advice and guidance before progressing to the next FamHC with the same family. To ensure construct validity, instruments measuring the core components of FamHCs were used: the HF-CQ® (Strömberg et al., 2017) and (ICE-FPSQ) (Swe) (Bruce et al., 2016), which were previously tested and found to be valid and reliable and of relevance to the aim and type of intervention in the study. No inferential statistics were performed due to the small sample size. Also, health care professionals’ increased attention and care for the participants may in part have caused the beneficial outcomes of the intervention rather than the intervention itself.

Lastly, threats to external validity (i.e., generalizability) concern the sample selection of participants and whether the results can be generalized to other RNs in other settings across time (Moore et al., 2012; Polit & Beck, 2014). Random sampling enhances generalizability, but purposive sampling (Etikan, Musa, & Alkassim, 2016) was used in study III, thus the results should be generalized with caution. On the other hand, being a multisite study in which the sites differ in important dimensions (e.g., size, level of care) empowers the generalizability of the results. Also, as the demographics of the participating RNs are described in detail, the reader can evaluate RNs’ representativeness of the general population of RNs. The RNs in the sample also reflect the total population of RNs in Sweden regarding age, gender and workplace (SoS, 2016).
This thesis highlights the divergence between FCs’ experiences and needs, and RNs’ perceptions about FCs’ situation and attitudes towards the importance of family involvement. It adds to the knowledge on the importance of RNs to acknowledge FCs as a resource and to support and involve them in HF nursing care. One feasible and successful way to support and involve families is to conduct Family Health Conversations via telephone in nurse-led HF clinics.

FCs’ daily lives were burdensome and characterized by uncertainty, but salutogenic behaviours restored their strength and motivation to care. The latter went, in general, unnoticed by RNs who focused on negative aspects of family caregiving. FCs experienced that health care professionals took family caregiving for granted without supplying the FCs with the appropriate tools to facilitate their situation. Neither were FCs invited to share information with health care professionals nor was their specific expertise requested. This gave rise to feelings of exclusion and had a negative influence on FCs’ relationship with their near one.

Previous research has found that RNs’ supportive attitudes towards families are requisites for involving families in nursing care. This thesis found that RNs who worked in PHCCs, in nurse-led HF clinics, with district nurse specializations, with education in cardiac and/or HF nursing care were predicted to have the most supportive attitudes towards family involvement in HF nursing care. Family Health Conversations via telephone in nurse-led HF clinics were found to successfully support and involve families in HF nursing care. Families and RNs found FamHCs to enhance the nurse-family relationship and relationships within the family. FamHCs also helped the RNs to acquire new and important information about the family as a whole, instead of solely focusing on the person with HF. FamHCs were found to be feasible for both families and RNs, although fewer and shorter FamHCs were preferred by RNs. Hence, FamHCs can be one way to successfully support and involve families in HF nursing care.
9 CLINICAL IMPLICATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

This thesis has generated new questions and ideas for clinical practice and future research in order to strengthen support for families in HF nursing care.

Suggestions for clinical practice and nursing education

- Provide families with the continuity and security of an RN as a permanent health care contact.

- Provide FCs with the opportunity of involvement in their near one’s health care and address issues of congruence and relationship quality within the family through the use of one to two FamHCs, irrespective of health care unit or type of organisation.

- Encourage experienced RNs in HF nursing care to mentor their younger, less experienced and less confident colleagues, and to demonstrate how they involve families in their own nursing practice.

- Implement the knowledge of family-centred nursing in nursing education on graduate and postgraduate level.

Suggestions for future research

- Evaluate RNs’ attitudes towards the importance of family involvement in HF nursing care before and after an intervention with FamHCs.

- Explore families’ and RNs’ experiences after a short FamHC as part of a regular HF health care meeting in a hospital ward, a nurse-led HF clinic in hospital, in a PHCC, in municipal elder care and in home health care.
10 SVENSK SAMMANFATTNING

**Bakgrund:** Hjärtsvikt är ett växande folkhälsoproblem relaterat till låg livskvalitet och betydande morbiditet och mortalitet. Stöd från familjen har positiva effekter på egenvård, hälsa och välbefinnande för personen med hjärtsvikt samtidigt som det kan leda till vårdgivarbörda och minskad livskvalitet för anhörigvårdaren. Sjuksköterskor träffar ofta anhörigvårdare till personer med hjärtsvikt i hälso- och sjukvården och har en nyckelroll i att möta behoven hos anhörigvårdare. Med tanke på den centrala roll familjen har för att förbättra hälsan och välbefinnandet hos personer med hjärtsvikt, behöver sjuksköterskor förberedas för de utmaningar och möjligheter som det innebär att stödja familjer som lever med svår långvarig sjukdom. **Syfte:** Det övergripande syftet med denna avhandling är att utforska situationen och behoven hos anhörigvårdare till personer med hjärtsvikt samt utforska förutsättningar för, och sätt att stödja och involvera anhörigvårdare i sjuksköterskans omvårdnad vid hjärtsvikt. **Metod:** Avhandlingen bygger på två kvalitativa intervjustudier (I+II), en kvantitativ webbenkätstudie (III) och en interventionsstudie (IV) genomförda mellan 2012 och 2017. Totalt har 22 anhörigvårdare, åtta personer med hjärtsvikt och 331 sjuksköterskor deltagit i studierna. Intervjuerna och interventionerna ägde rum på tre sjukhus och tre vårdcentraler i ett län. I webbenkäten deltog sjuksköterskor från 47 sjukhus och 30 vårdcentraler i olika delar av Sverige. **Resultat:** Anhörigvårdares dagliga liv präglades av oro, ovisshet samt inkongruens i relationen till den närstående med hjärtsvikt, men salutogena beteenden användes för att bygga upp ny kraft och motivation att vårda. Anhörigvårdare upplevde att hälso- och sjukvårdpersonal tog anhörigvården för given utan att tillhandahålla stöd och lämpliga verktyg. Anhörigvårdare delgavs inte information och deras egen expertis efterfrågades inte. Detta gav upphov till känslor av utanförskap och hade en negativ inverkan på relationen mellan anhörigvårdaren och dennes närstående. Anhörigvårdare uttryckte ett behov av en fast vårdkontakt och en större involvering tillsammans med hälso- och sjukvårdspersonal i planering och genomförande av den närståendes sjukvård (I). Sjuksköterskor bekräftade anhörigvårdares vårdgivarbörda, deras brist på kunskap och inkongruens i relationen till den närstående. För
att förbättra kontinuitet och trygghet för anhörigvårdare föreslog de en namngiven sjuksköterska som fast vårdkontakt. Sjuksköterskor uppmärksammade inte anhörigvårdare som en resurs eller deras behov av involvering med hälso- och sjukvårdpersonal (II). Tidigare forskning har funnit att sjuksköterskors stödjande attityder till familjer är förutsättningar för att involvera familjer i omvårdnaden. Denna avhandling fann att sjuksköterskor som arbetade på vårdcentral, på sjuksköterskeledda hjärtsviktsmottagning, med distriktssköterskespecialisering, med utbildning inom kardiologisk omvårdnad var de mest sannolika att ha de mest stödjande attityderna till familjens involvering i omvårdnaden vid hjärtsvikt (III).

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