Doctoral Thesis

Partner Relationship in Couples Living with Atrial Fibrillation

Tomas Dalteg
Science is the first expression of punk, because it doesn't advance without challenging authority. It doesn't make progress without tearing down what was there before and building upon the structure.

Greg Graffin, PhD and lead vocalist of Bad Religion.
Abstract

The aim of this thesis was to describe and explore how the partner relationship of patient–partner dyads is affected following cardiac disease and, in particular, atrial fibrillation (AF) in one of the spouses.

The thesis is based on four individual studies with different designs: descriptive (I), explorative (II, IV), and cross-sectional (III). Applied methods comprised a systematic review (I) and qualitative (II, IV) and quantitative methods (III). Participants in the studies were couples in which one of the spouses was afflicted with AF. Coherent with a systemic perspective, the research focused on the dyad as the unit of analysis. To identify and describe the current research position and knowledge base, the data for the systematic review were analyzed using an integrative approach. To explore couples’ main concern, interview data (n = 12 couples) in study II were analyzed using classical grounded theory. Associations between patients and partners (n = 91 couples) were analyzed through the Actor–Partner Interdependence Model using structural equation modelling (III). To explore couples’ illness beliefs, interview data (n = 9 couples) in study IV were analyzed using Gadamerian hermeneutics.

Study I revealed five themes of how the partner relationship is affected following cardiac disease: overprotection, communication deficiency, sexual concerns, changes in domestic roles, and adjustment to illness. Study II showed that couples living with AF experienced uncertainty as the common main concern, rooted in causation of AF and apprehension about AF episodes. The theory of Managing Uncertainty revealed the strategies of explicit sharing (mutual collaboration and finding resemblance) and implicit sharing (keeping distance and tacit understanding). Patients and spouses showed significant differences in terms of self-reported physical and mental health where patients rated themselves lower than spouses did (III). Several actor effects were
identified, suggesting that emotional distress affects and is associated with perceived health. Patient partner effects and spouse partner effects were observed for vitality, indicating that higher levels of symptoms of depression in patients and spouses were associated with lower vitality in their partners. In study IV, couples’ core and secondary illness beliefs were revealed. From the core illness belief that “the heart is a representation of life,” two secondary illness beliefs were derived: AF is a threat to life, and AF can and must be explained. From the core illness belief that “change is an integral part of life,” two secondary illness beliefs were derived: AF is a disruption in our lives, and AF will not interfere with our lives. Finally, from the core illness belief that “adaptation is fundamental in life,” two secondary illness beliefs were derived: AF entails adjustment in daily life, and AF entails confidence in and adherence to professional care.

In conclusion, the thesis result suggests that illness, in terms of cardiac disease and AF, affected and influenced the couple on aspects such as making sense of AF, responding to AF, and mutually incorporating and dealing with AF in their daily lives. Altogether, the results from the thesis indicate that clinicians working with persons with AF and their partners should employ a systemic view with consideration of the couple’s reciprocity and interdependence but also have knowledge regarding AF. A possible approach to achieve this is a clinical utilization of an FSN based framework, such as the FamHC. Clinicians operating at in-hospital settings should invite partners to participate throughout the hospital stay regarding rounds, treatment decisions and discharge calls, whilst clinicians in primary care settings should invite partners to participate in follow-up meetings. Likewise, interventional studies should include the couple as a unit of analysis as well as the target of interventions.
Original papers

The thesis is based on the following papers, which are referred to by their Roman numerals in the text:

Paper I

Paper II

Paper III

Paper IV

The articles have been reprinted with the kind permission of the respective journals.
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Tomas Dalteg
Introduction

As humans, we live in systems, or social constructs and environments, in which our actions affect other people directly and/or indirectly; likewise, other people influence and affect us through their actions and behavior (Watzlawick, Beavin, & Jackson, 1967; Maturana & Varela, 1992). Consequently, becoming afflicted with a chronic illness has implications not only for the afflicted person but also for people close to that person. As persons involved in a close relationship can be seen as a reciprocal system, this thesis focuses on the couple – or dyad – as the unit of analysis. When a couple becomes afflicted with illness, they are confronted with the notion of making changes in their routines to incorporate the illness as well as facing a potentially altered future (Knafl & Gillis, 2002). Thus, illness has the potential to either be detrimental or present an opportunity for growth in the couple’s partner relationship (Rolland, 1994). One of the most frequent chronic illnesses is cardiovascular disease, which is also the most common cause of death worldwide and accounted for nearly 17.5 million deaths in 2012, 6.7 million of which were due to stroke (World Health Organization [WHO], 2016). One of the largest independent risk factors of suffering from a stroke is atrial fibrillation (AF); a cardiac arrhythmia associated with a fivefold increased risk of stroke (Go et al., 2014; January et al., 2014). Recent estimates of AF assert a prevalence of 3% in adults 20 years old or older (Kirchhof et al., 2016), which is expected to double by the year 2060 (Krijthe et al., 2013). Persons with AF have been reported to have worse quality of life than the general population (Kang & Bahler, 2004; Thrall, Lane, Carroll, & Lip, 2006) and persons with other coronary artery diseases (Thrall et al., 2006). Persons with AF have also reported to experience lower personal control over the illness compared to other cardiovascular diseases (McCabe, Barnason, & Houfek, 2011), and are twice as likely to be hospitalized compared to age- and sex-matched control subjects (Go et al., 2014). To date, AF is fairly well researched from a medical perspective (Kirchhof et al.,
2016), but little is known about what it is like to live with AF (Altiok, Yilmaz, & Rencüsoğullari, 2015; McCabe, Schumacher, & Barnason, 2011) and its implications for daily life of patients and relationships with persons close to them. However, some studies have reported that AF not only affects the patient but also has implications for the partner in terms of feelings of worry (Ekblad, Malm, Fridlund, Conlon, & Ronning, 2014), interruption of daily activities (Coleman et al., 2012), and equal levels of suffering as those of patients (Bohnen et al., 2011).

Traditionally, health-care institutions and professionals tend to put focus on the individual and not on the system. As such, this thesis intends to put focus on the system – or at least a part of the system – namely, the couple. If the formalized and professional care of persons with AF and their partners are to be thoroughly substantiated, research is needed on how the couple perceives the illness in their relationship and daily living and its consequences as well as how they handle their situation. These issues will be addressed in this thesis.
Background

The Association between Close Relationships and Health and Illness

Within the field of family research, it is well recognized that there exists an association between close relationships and health and well-being. A great deal of literature has demonstrated that being part of close relationships, such as being married or having a partner, is protective against chronic conditions (Berkman & Syme, 1979; Callaghan & Morrissey, 1993; Kilpi, Konttinen, Silventoinen, & Martikainen, 2015; Stadler, Snyder, Horn, Shrout, & Bolger, 2012). Within their meta-analytic review of 148 studies, Holt-Lunstad, Smith, and Layton (2010) concluded that deficits in close relationships increase the risk for mortality and that these effects are comparable to other well-established risk factors, such as tobacco use, physical inactivity, or obesity. In contrast to persons who are single, couples tend to have a lower mortality rate as well as a higher survival rate in the event of a chronic condition (Kowal, Johnson, & Lee, 2003). While it has been reported that men appear to benefit more from having a partner or entering marriage than women do (Staehelin, Schindler, Spoerri, & Zemp Stutz, 2012; Williams & Umberson, 2004), contrary findings have also been reported. In their study on pooled data from the National Health Interview Survey (NHIS), comprising 1,119,266 observations ranging from 1973 to 2003, Liu and Umberson (2008) found no support that men benefitted more than women from marriage over time. Apart from the positive aspects of being married or having a partner, Kiecolt-Glaser and Newton (2001) expressed that negative aspects of marital functioning have indirect influences on health through depression and health habits and direct influences on physiological mechanisms such as cardiovascular, endocrine, and immune function. Thus, being in a close relationship is not alone a guarantee for health and well-being; the
quality of the close relationship also interplays where distressed couples with many conflicts may have adverse effects on health (Kowal et al., 2003; Robles & Kiecolt-Glaser, 2003). Additionally, specific relationship behaviors may implicate adverse effects on health, such as the way partners behave with each other. Hostile interactions, contemptuous facial expressions, or critical remarks are some examples that may have adverse effect on health and well-being. Accordingly, De Vogli, Chandola, and Marmot (2007) found that adverse close relationships, in terms of negative interactions, may increase the risk of coronary heart disease. In their review of 126 studies, Robles, Slatcher, Trombello, and McGinn (2014) found that greater marital quality and satisfaction was related to better perceived health.

Thus, the association between close relationships and health and illness cannot be disregarded and is therefore an aspect that cannot – and should not – be neglected within health and care sciences. As research on close relationships to a great extent concerns the field of couple/marriage and the family (Hendrick, 2004), it is suitable to scrutinize what actually characterizes a family and how the family may be regarded within health and care sciences.

Close Relationships in Health and Care Sciences

There are several ways, differing among disciplines, to define the close relationship that constitutes a family; from a legal perspective, it concerns relationships through blood ties, adoption, guardianship, or marriage; from a biological perspective, through genetic biological networks among people; from a sociological perspective, people living together; and from a psychological perspective, groups with strong ties to each other (Hanson, 2005). Combined, a family may be defined as a group of people linked together by strong emotional ties, a sense of belonging, and mutual engagement in each other’s lives. According to Wright and Leahey (2013), five characteristics can be used to describe a family: (i) the family is a system or a unit; (ii) the members do not have to be related to each other, nor do they have to live together; (iii) the family unit may contain children; (iv) there is commitment and
attachment among the members that include future obligation; and (v) the family unit’s caregiving functions consist of protection, nourishment, and socialization of its members. Such a description enables a broad approach to what actually constitutes a family – mother/father/child, single parent, non-married/married couples living together with/without children, heterosexual couples, gay couples, etc. Family connectedness and fellowship, therefore, need not be tied to consanguinity; the family itself decides its structure and members (Whall, 1986; Wright & Leahey, 2013).

Within health and care sciences, family nursing can be seen as a specialty area that cuts across the various aspects of other specialty areas of nursing. According to Kaakinen and Hanson (2015), there are four perspectives that may characterize the nursing of families. **Family as a context** is when the family is viewed as a context for the patient; the family is in the background and considered to be a resource or a stressor for the patient. **Family as client** focus upon how the family members individually are affected by illness in one of the family members. **Family as a component of society** refers to when the family is viewed as a subsystem within a larger system, such as community or society; focus is upon how the family interacts with other institutions. **Family as system** views the family as a system where the family as a whole is considered as the client; the family is viewed as an interactional and reciprocal system where the whole is more than the sum of its parts. Focus is upon the individual and family simultaneously, for example, the interaction between couples as patient–partner dyads. The described aspects are not mutually exclusive, but, rather, the different perspectives all have legitimate implications for persons working with families.

**The Family as a System**

The term Family Systems Nursing (FSN) was coined by family nursing scholars Lorraine Wright and Maureen Leahey in the 1980s. Attentiveness is given to both the individual and the family with focus on interaction and reciprocity (Bell, 2009). As no model or theory alone
can be used to explain FSN, it draws on different theories and frameworks (Wright & Leahey, 2013).

Within general systems theory, a system can be defined as a set of elements standing in interaction with each other (von Bertalanffy, 1968). Inherent to this theory is the notion of wholeness, which designates that every part of a system is related to its fellow parts so that a change in one part will cause change in all of them and in the total system. In other words, a system behaves coherently and as an inseparable whole (Watzlawick, Beavin, & Jackson, 1967). Thus, a systemic approach, following the Aristotelian worldview, is characterized by the notion that the whole is more than the sum of its parts (von Bertalanffy, 1972). This may be illustrated by describing the systemic way of thinking through a mobile that consists of several parts; when one of the parts moves, it affects the whole mobile (Wright & Leahey, 2013). That is, when a family member is afflicted with illness, this, in turn, has an implication for and effect on the whole family. Closely related to systems theory is cybernetics, which is the theory of control systems based on transfer of information between system and environment and within the system and feedback of the system's function with regard to environment (von Bertalanffy, 1968). Thus, cybernetics encompasses feedback loops, which contrast a linear way of viewing interaction in favor of a circular view of interaction. A traditional deterministic linear system assumes that \( a \) affects \( b \) and \( b \) affects \( c \), which, in turn, affects \( d \). If \( d \) then affects \( a \), the notion of circularity (or feedback) is present. From this, the family can be seen as an interpersonal system in which an individual family member’s behavior affects other family members, and, likewise, the individual is affected by other family members’ behavior (Watzlawick et al., 1967). A couple can be viewed as a system containing two individuals that are structurally coupled, i.e., recurrent interaction between the two leads to structural congruence between the two, which can be seen as the behavior of one becoming a function of the behavior of the other (Maturana & Varela, 1992). Moreover, structural coupling includes the interaction between the couple and the environment in which they
experience a mutual history of evolutionary changes and transformations (Proulx, 2008). While systems theory bring focus from parts to wholes, cybernetics brings focus from substance to form (Wright & Leahey, 2013); in other words, systems theory focus on structure while cybernetics focuses on function. Changes or alterations in a family system occur as a result of a disturbance, such as illness in a family member (Wright & Leahey, 2013). Each individual has its own unique structure that has evolved from its genetic history as well as through historical interactions with the environment and other individuals. The same applies to couples that have a unique structure evolved through historical interactions with the environment. Following this, a couple can be viewed as a living system that is structurally determined, which means that it is not the perturbation itself (e.g., illness) that determines what happens to a living being; it is, rather, the inherent and evolved structure that determines what happens in it (Maturana & Varela, 1992). Accordingly, a structure-determined system – when faced with a disturbance – may either have a structural change or disintegrate (Maturana, 1978). As such, recurrent interactions between the living system and the disturbance will result in a history of mutual congruent structural changes in which the system adapts (Proulx, 2008). In other words, the structural changes that the couples undergo through structural coupling with its environment may be seen as adaptive responses. This corresponds with Bateson (1998), who states that an organized system (e.g., human organization) is self-regulating in the sense that, when something disturbs its boundaries, the system adjusts to maintain balance.

The Couple as a Family Subsystem

A couple is a family subsystem that, in a sense, is the composition of three families coming together; the two partners’ family of origin and the new couple (Wright & Leahy, 2013). Consequently, a relationship per se is manifested through the interaction between individuals in which one person’s behavior or action has an implication for and/or effect on the other person (Cook, 2001) while a partner relationship may
be conceptualized as a romantic notion between two individuals manifested through dating, cohabiting, or marriage (Hendrick & Hendrick, 2006). The couple may be seen to be in a committed relationship in which they, throughout the course of their relationship, develop routines and traditions on aspects such as recreation, eating habits, and use of space and time. Moreover, the development of the couple may be seen to include the blending of individual needs, development of conflict-and-resolution approaches, and communication and intimacy patterns (Kaakinen & Hanson, 2015). According to Reis and Collins (2000), there are three aspects that may describe the relationship between two partners. Perceived partner responsiveness (e.g., intimacy, trust, and empathy) concerns feelings of being understood, validated, and cared for by a partner who is aware of the facts and feelings central to one’s self-conception. Nature and extent of interdependence (e.g., closeness and commitment) concerns the degree and type of casual influence each partner has on the other. Sentiment (e.g., love, satisfaction, and conflict) concerns manifestations of partners’ affect toward each other.

Even though close relationships contain supportive features, it is sensible to differentiate social support from relationship processes. Supportive interactions involve attempts to provide assistance in response to expressed or perceived distress (Thoits, 1986) while a relationship process that involves intimacy encompasses behavior other than helping and is not usually conditioned by distress (Reis & Collins, 2000). Intimacy, in a broad sense, may relate to different aspects in a relationship such as sharing feelings, sharing responsibilities, sharing interests, and mutual protection (Rolland, 1994). When a couple becomes afflicted with illness, they are confronted with the notion of making major changes in their routines to accommodate the illness as well as facing a potentially altered future (Knafl & Gilliss, 2002). Thus, illness has the potential of being either detrimental or presenting an opportunity for growth in the couple’s relationship (Rolland, 1994).
The Association between Chronic Illness and Close Relationships

The above sections have described the association between close relationships and health and illness. On the other hand, the above association can also be seen to be inverted, i.e., illness is associated with couples’ close relationships. As such, an illness that ends in a relatively short time may be regarded as an acute illness while an illness that continues indefinitely may be regarded as a chronic condition (Larsen, 2009). As cardiovascular disease and AF can be regarded as chronic conditions (McCabe, 2011), it is suitable to scrutinize what a chronic illness is and the different forms that may be used to characterize chronic illnesses.

The Characteristics of Chronic Illness

To begin with, there is a distinct difference between the terms disease and illness concerning a chronic condition. The term “disease” refers to a condition that is viewed from a medical or pathophysiologic perspective with focus on structure and function while the term “illness” refers to the human experience of symptoms and how the condition is perceived, lived with, and responded to by individuals and families (Larsen, 2009). The characteristics of a chronic condition can be described as being permanent, giving a lasting disability, being caused by a non-reversible pathological change, and involving special training and rehabilitation (Strauss & Corbin, 1984). From this, the course of chronic conditions may be divided into three different forms: (i) progressive, which means that the condition continually progresses in severity; (ii) constant-course, which means that, after the onset, the course stabilizes, though with some possible functional limitations; and (iii) relapsing or episodic, which means that there are stable periods with low levels or absence of symptoms and periods with occurrence or exacerbation of symptoms (Rolland, 1987). Thus, a chronic condition may have either a predictable or unpredictable progression and development. In general, a chronic condition results in changes not only
to physical and psychological functioning but also to occupational and social roles in work, family life, friendships, and leisure (D'Ardenne, 2004). According to Rolland (1994), there is a risk that chronic conditions can have an insidious impact on relationships in that all interactions will become fused with the illness.

**Impact of Chronic Illness on Couples Relationship and Daily Life**

When a couple becomes afflicted with a chronic illness, it affects their social identity, roles, financial security, and plans for the future (Baanders & Heijmans, 2007; D'Ardenne, 2004; Eriksson & Svedlund, 2006; Rees, O'Boyle, & MacDonagh, 2001). Studies have also shown that chronic illness may alter the relationship dynamics, causing a shift in occupational household duties (Aasbø, Solbraekke, Kristvik, & Werner, 2016; Boyle, 2009; D'Ardenne, 2004; Eriksson & Svedlund, 2006; Pretter, Raveis, Carrero, & Maurer, 2014). Moreover, studies have also shown that couples’ ability and possibility to perform and engage in social and physical activities are reduced or limited as a consequence of the patients’ chronic illness (Aasbø et al., 2016; Ahlström, 2007; Boyle, 2009; Eriksson & Svedlund, 2006; Kralik, Telford, Price, & Koch, 2005; Pretter et al., 2014). Apart from social effects, chronic illness has been reported to have negative influence on the intimate relationship and sexual satisfaction (D'Ardenne, 2004; McInnes, 2003), resulting from misconceptions about sexual ability, sexual dysfunction as a consequence of medication, or fear or resuming sexual activities (Nusbaum, Hamilton, & Lenahan, 2003; Steinke & Swan, 2004). Additionally, the illness may cause interference that causes members of the couple to talk less; it may also be that they avoid specific topics out of concern for the other (e.g., to appear positive, to avoid saying the wrong thing, or to provide protection from worry) (Checton, Greene, Magsamen-Conrad, & Venetis, 2012). Regardless of the reason for avoiding certain topics, couples’ perceptions of – or beliefs about – an illness in their lives influence their perceived ability to talk about (Checton et al., 2012) and handle the illness (Wright & Bell, 2009). Thus, couples’ mutual or shared beliefs are important in
the process of adaptation to an illness, as highlighted in the model by Patterson (1989), as it contributes to a better health outcome for both members of the couple (Trump & Mendenhall, 2016). Couples that share similar positive beliefs have reported better psychological adjustment (Figueiras & Weinman, 2003; Sterba et al., 2008), lower levels of disability and fewer sexual problems, higher vitality, less health distress, and less impact on recreational and social activities (Figueiras & Weinman, 2003).

The onset of a chronic condition is, in general, seen to be a negative life event that have adverse effects – patients and partners have to cope and to incorporate the condition into their life which may alter the way they interact (Kowal et al., 2003). However, the onset of chronic condition may bring an opportunity for relationship growth (Rolland, 1994). As such, couples have reported an increased closeness within their partner relationship following affliction with a chronic illness (Baanders & Heijmans, 2007; Mutch, 2010; Pretter et al., 2014; Radcliffe, Lowton, & Morgan, 2013; Söderberg, Strand, Haapala, & Lundman, 2003). According to Knafl and Gilliss (2002), most families, over time, are able to find positive meaning in the illness experience and incorporate illness management into their everyday routine so that life resumes or retains a taken-for-granted quality.

Noticeably, a great deal of literature has described implications and consequences of couples’ relationships and daily lives following chronic illness. Even though there are different forms of chronicity (i.e., progressive, constant, or relapsing), similar implications have been reported in the literature across the different forms (e.g., interference in social life and activities, shift in household duties, anxiety and depression, avoidance of talking, or increased closeness). Thus, the initiation of a chronic illness – regardless of type – has implications and consequences in the couple’s life. However, in their early review, Kriegsman, Penninx, and van Eijk (1994) argued that differences between the impact of the chronic illness with respect to health and functioning can be explained by disease-specific characteristics, such as cognitive disturbances in the patient or the degree to which persons
are able to influence prognosis. A particular contrast in living with a relapsing chronic illness – such as multiple sclerosis (MS) or chronic obstructive pulmonary disease (COPD) – is the aspect of uncertainty and ambiguity regarding episodic exacerbation or the sudden appearance of symptoms (Boland, Levack, Hudson, & Bell, 2012; Boyle, 2009; Ek, Ternestedt, Andershed, & Sahlberg-Blom, 2011; Mishel, 1999; Mutch, 2010; Rolland, 1987). However, it should be noted that the various challenges couples face may differ depending on the nature of the onset, level of incapacitation and prognosis of the illness, treatment regime, current medical knowledge, interactions with professionals, positions in the lifecycle, and previous experiences of illness (Altschuler, 2015; Berg & Upchurch, 2007; Rolland, 1994).

The Chronicity of Atrial Fibrillation

AF is a supraventricular tachyarrhythmia with uncoordinated atrial activation and consequently ineffective atrial contraction (January et al., 2014). In contrast to other cells, cardiac cells are capable of self-stimulation. Although this ability is protective if the heart’s conduction system fails, it can also cause ectopic activity in the cardiac cells and result in AF. In AF, multiple atrial cells self-stimulate, behaving as individual pacemakers and competing with the sinoatrial node for control of cardiac activity. Normal atrial contractions are replaced by rapid quivering movements, and the atria stop contracting effectively (Cutugno, 2015). AF is a common cardiac arrhythmia that may be classified in the following categories: paroxysmal AF, in which the patient has recurrent AF episodes that terminate spontaneously in less than seven days; persistent AF, in which the patient has recurrent AF episodes that last more than seven days; permanent AF, in which the patient has long-standing AF for more than one year, and pharmaceutical treatment or cardioversion do not alter the state (January et al., 2014). From this, it may be stipulated that AF contains both constant-course (permanent AF) and episodic (paroxysmal AF and persistent AF) forms of chronicity.
The estimated prevalence of AF in the world is about 3% in adults 20 years old or older (Kirchhof et al., 2016) with greater prevalence in older persons and higher prevalence in men compared to women (Chugh et al., 2014). Similar data have been reported regarding Sweden with an estimated prevalence of 3% as well as greater prevalence in older persons and higher prevalence in men compared to women (Björck, Palaszewski, Friberg, & Bergfeldt, 2013). The number of patients with AF is expected to more than double by 2060 (Krijthe et al., 2013), which may be due to an increase in the aging population as well as improved detection of AF (Kirchhof et al., 2016). Moreover, patients with AF are approximately twice as likely to be hospitalized as age- and sex-matched control participants (Go et al., 2014). Risk factors associated with the development of AF are increased age, hypertension, heart failure, valvular heart disease, diabetes mellitus, coronary artery disease, chronic obstructive pulmonary disease, and sleep apnea (Camm et al., 2012). The 2014 guidelines for the management of patients with AF (January et al., 2014) stipulate that AF is associated with a fivefold increased risk of stroke where AF-related stroke is likely to be more severe than non-AF-related stroke; AF is also associated with a threefold risk of developing heart failure and a twofold increased risk of both dementia and mortality.

Management of AF is concerned with reducing symptoms and preventing complications. To prevent stroke, most patients require lifelong medication with oral anticoagulation drugs (traditionally the K-vitamin antagonist warfarin). Usage of warfarin reduces the risk of stroke by 65% in patients with AF (Hart, Pearce, & Aguilar, 2007). Recently, newer oral anticoagulants have been introduced that do not require dietary restrictions (i.e., food that contains vitamin K) or repeated and continuous INR testing (international normalized ratio testing; a higher value indicates that it takes longer for the blood to clot). However, the new oral anticoagulants require strict compliance as one missing dose could result in a period without protection from thromboembolism (January et al., 2014). Apart from anticoagulation therapy, rate and rhythm control are important in the management of
AF. Nonpharmacological treatment of AF involves electrical cardioversion, in which electric shocks are fired through the heart to restore sinus rhythm, and catheter ablation, in which the area in the left atria that causes the AF is isolated. However, the underlying cause and sustaining force of AF are multifactorial, and AF can be complex and difficult for professionals to manage.

The 2016 guidelines for the management of patients with AF specify that most persons with AF require regular follow-up by a cardiologist and/or specialist nurse to ensure optimal management (Kirchhof et al., 2016). Yet there are no specific formal guidelines that stipulate the nursing of persons with AF. However, it has been proposed that the nursing of persons with AF is to be focused on education and counselling that address (i) causes of AF, (ii) consequences of AF, (iii) course of AF, (iv) treatment, (v) action planning, and (vi) psychosocial response to AF (McCabe, 2011).

**Living with Atrial Fibrillation – patient and partner perspective**

Persons living with AF may experience symptoms such as palpitations, breathlessness, chest pain, and dizziness (Freeman et al., 2015; McCabe, Chamberlain, Rhudy, & DeVon, 2016), which may limit their strength, stamina, and lifestyle and impose feelings of uncertainty in their lives (Kang, 2005, 2006). Previous studies have reported that persons with AF have lower quality of life than the general population (Kang & Bahler, 2004; Thrall et al., 2006) and persons with other coronary artery diseases (Thrall et al., 2006). Persons with AF have also reported experiencing lower personal control over the illness compared to other cardiovascular diseases (McCabe, Barnason et al., 2011). As such, persons with AF may experience limitations in daily life and social activities (Ekblad, Ronning, Fridlund, & Malm, 2013) in terms of refraining from going on holiday or visiting friends (Altikok et al., 2015) or not being able to exercise to the same extent as previously (McCabe, Schumacher et al., 2011). Studies have also reported that persons with AF try to identify traits that can explain the initiation of AF episodes, such as certain foods, beverages, or situations (Ekblad et al., 2013; McCabe, Schumacher, et al., 2011). Additionally, it has been
reported that persons afflicted with AF suffer psychologically in the form of anxiety, fatigue, and depression (Deaton, Dunbar, Moloney, Sears, & Ujhelyi, 2003; McCabe, 2008, 2010; Thrall, Lip, Carroll, & Lane, 2007) and have poor knowledge about the disease and its treatment (Koponen et al., 2008). The findings from Ekblad et al. (2013) suggest that the bodily impact of AF gives rise to existential distress in terms of a constant worry and concern, which is draining. Studies has also shown that persons who perceive AF as unpredictable experience more negative emotions (McCabe, Schumacher, et al., 2011) but also that negative emotions are linked to greater AF symptomology (Sears et al., 2005). Additionally, emotional distress has previously been linked as a predictor for impaired quality of life in persons living with AF (Ong et al., 2006; Thrall et al., 2007). There is also a relationship between psychological distress in the form of anxiety and impaired quality of life (McCabe, 2010).

Seemingly, AF has a profound impact on several aspects of life in persons with AF. Altiok et al. (2015) reported that persons with AF experienced an increased dependence on family and relatives after being diagnosed with AF. However, there is limited knowledge of how partners of patients with AF are affected following the initiation of the condition. Bohnen et al. (2011) found that spouses are affected in similar ways as those with AF, and the perceived impact on quality of life is similar. Ekblad et al. (2014) found that partners worried for the patients as well as having to giving up on their own needs. Coleman et al. (2012) found that the partners experienced significant interruption in daily activities due to the patients’ AF. This indicates that, although the AF symptomology can be very limiting for the patient, it is also limiting to the person who lives closely with a person with AF. As such, the onset of a chronic condition – such as AF – may challenge the emotional and physical boundaries of a couple’s relationship; the illness may be viewed as an uninvited guest that the couple needs to relate to and incorporate in their life (Rolland, 1994).
Rationale of the Thesis

The relevance and significance of close relationships are not easily dismissed. On one hand, it affects health and well-being, and, on the other hand, illness also affects close relationships. Previous research on chronic illness has shown several implications for the partner relationship, though there is a paucity of research in the contextual perspective of living with AF – how they experience the disease in their daily living and how they handle the disease. As such, persons with AF have poorer quality of life and are more often hospitalized than the general population and those with other cardiac conditions. Additionally, partners of persons with AF have reported feelings of worry, interruptions of daily activities, and equal levels of quality of life as patients. Combined, this promotes an incentive to target research on both persons with AF and their partners. If the formalized and professional care of persons with AF and their partners is to be thoroughly substantiated, research is needed into how their daily lives and relationships are affected – both in order to generate knowledge and to be able to create appropriate interventions.
Aims of the Thesis

The overall aim was to describe and explore how the partner relationship of patient–partner dyads is affected following cardiac disease and, in particular AF, in one of the spouses. The following specific aims were postulated for the individual studies:

I. Identify how the partner relationship is affected following cardiac disease after hospital discharge.

II. Explore couples’ main concern when one of the spouses has AF and how they continually handle it within their partner relationship.

III. Examine if emotional distress in patients with AF and their spouses was associated with their own and their partner’s perceived health.

IV. Explore illness beliefs in couples where one of the spouses is afflicted with AF.
Methodology

Design

Following the specific individual research aims, the thesis utilized different research designs and methods: descriptive (I), explorative (II, IV), and cross-sectional (III). Applied methods comprised a systematic review (I) as well as qualitative (II, IV) and quantitative methods (III). Coherent with a systemic perspective, the research focused on the dyad as the unit of analysis. An overview of the individual studies is illustrated in Table 1.

The first study applied a descriptive design in terms of a systematic literature review in order to identify and describe the current research position and knowledge base (Polit & Beck, 2004). Results from study I initiated the utilization of an explorative design in terms of a classical grounded theory study (II), a qualitative method suitable when a phenomenon is not well understood (e.g., when there is a paucity of research) (Polit & Beck, 2004). Combined, the results from studies I and II initiated a focus to examine associations of emotional distress and perceived health between patients and partners; thus, a quantitative cross-sectional design was deemed appropriate as it allows for describing associations among phenomena at a fixed point in time (Polit & Beck, 2004). From the results in studies I–III, an additional explorative design was initiated in terms of qualitative hermeneutic study to explore and interpret couples’ mutual illness beliefs.
<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Sample</th>
<th>Data Collection</th>
<th>Data Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Identify how the partner relationship is affected following cardiac disease after hospital discharge</td>
<td>Descriptive</td>
<td>20 articles</td>
<td>PubMed; CINAHL; PsycINFO; reference tables</td>
<td>Integrative analysis</td>
</tr>
<tr>
<td>II</td>
<td>Explore couples’ main concern when one of the spouses has AF and how they continually handle it within their partner relationship</td>
<td>Explorative</td>
<td>12 couples in which one of the spouses was afflicted with AF</td>
<td>Interviews with couples</td>
<td>Classical Grounded Theory</td>
</tr>
<tr>
<td>III</td>
<td>Examine if emotional distress in patients with AF and their spouses was associated with their own and their partner’s perceived health</td>
<td>Correlational</td>
<td>91 couples in which one of the spouses was afflicted with AF</td>
<td>Self-report questionnaires; SF-36 and HADS</td>
<td>Actor–Partner Interdependence Model using Structural Equation Modeling; Wilcoxon Signed Ranks Test; Spearman’s correlation</td>
</tr>
<tr>
<td>IV</td>
<td>Explore illness beliefs in couples where one of the spouses is afflicted with AF</td>
<td>Explorative</td>
<td>9 couples in which one of the spouses was afflicted with AF</td>
<td>Interviews with couples</td>
<td>Hermeneutic analysis</td>
</tr>
</tbody>
</table>
Participants (II–IV)

Participants were recruited from a medical emergency ward (II), four different cardiac care units (III), and an out-patient cardiac care unit (IV) in the south of Sweden. An overview of the participating couples is illustrated in Table 2. Inclusion criteria for participating couples were the same in studies II–IV: patient diagnosed with AF, both patient and partner ≥18 years of age, engaged in a partner relationship, both patient and partner willing to participate. Couples were excluded from participation if one of the spouses was affected with severe chronic illness (e.g., dementia or mental illness).

Settings and Procedures (II–IV)

Eligible patients for studies II and IV were asked to participate by a study recruitment nurse who provided oral information regarding the aim of the study, procedure for data collection, and that the study involved both the patient and the partner. If patients were interested, the study recruitment nurse forwarded the information to the main researcher (i.e., the author of this thesis), who contacted the patient via telephone to provide additional information regarding the study. If patients gave consent to participate, partners were asked to participate and given the same information. Thus, participation relied on patients’ initial consent to participate. In addition to the oral information, a letter of information was sent to the couples describing the aim of the study, procedure for data collection, voluntary participation, and that they could withdraw from participation at any time without having to disclose a reason why.

Interviews were done in Swedish with 12 (II) and 9 couples (IV) and were recorded and transcribed verbatim. Couples were free to decide the location of the interview. Interviews were conducted in the couples’ home or at an office at the university. Data for study II were collected during the fall of 2011 and spring of 2012 while data for study IV were collected during the fall of 2015.
Eligible patients for study III were asked for participation by a study recruitment nurse who provided oral and written information about the aim of the study, procedure for data collection, and voluntary participation. Patients were informed that the study also involved the partner. If patients gave consent to participate, the study recruitment nurse asked the partner to participate. Thus, participation in the study relied on patients’ initial consent to participate. After consent to participate was given, a study recruitment nurse in the cardiac care unit at the respective hospital administered questionnaire packages that included questions covering demographic characteristics, emotional distress, and perceived health. Patients and spouses were informed not to discuss their answers while completing the questionnaires. Completed questionnaires were returned by post to the first author of the study. Patients’ medical histories were collected by the study recruitment nurse from patients’ medical records. Data were collected between 2010 and 2013 as part of a larger multicenter project (Structured Management and Coaching for Patients with Atrial Fibrillation – SMaC-PAF) initiated at the County Hospital Ryhov in Jönköping, Sweden. The present study used baseline data that comprised patient and partner as a matched couple. In total, 91 couples participated in the study.
Table 2. Characteristics of the Participants in Studies II–IV

<table>
<thead>
<tr>
<th>Study</th>
<th>n</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study II (n = 12 couples)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s age (years)</td>
<td>12</td>
<td>63.6 (8.8)</td>
<td>51–78</td>
</tr>
<tr>
<td>Patient’s sex (male/female)</td>
<td>8/4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner’s age (years)</td>
<td></td>
<td>61.8 (9.2)</td>
<td>47–77</td>
</tr>
<tr>
<td>Partner’s sex (male/female)</td>
<td>4/8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time together as partners (years)</td>
<td></td>
<td>38.3 (10.2)</td>
<td>23–59</td>
</tr>
<tr>
<td>Married/cohabiting, no children living at home</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting with children living at home</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since AF diagnosis (years)</td>
<td></td>
<td>3.5 (4.1)</td>
<td>0–13</td>
</tr>
<tr>
<td><strong>Study III (n = 91)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s age (years)</td>
<td>91</td>
<td>66.0 (9.0)</td>
<td>38–82</td>
</tr>
<tr>
<td>Patient’s sex (male/female)</td>
<td>57/34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner’s age (years)</td>
<td></td>
<td>65.0 (10.6)</td>
<td>38–87</td>
</tr>
<tr>
<td>Partner’s sex (male/female)</td>
<td>34/57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time together as partners (years)</td>
<td></td>
<td>37.5 (15.5)</td>
<td>4–63</td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>89</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partners, not living together</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since AF diagnosis (years)</td>
<td></td>
<td>7.3 (7.7)</td>
<td>0–33</td>
</tr>
<tr>
<td><strong>Study IV (n = 9 couples)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s age (years)</td>
<td>9</td>
<td>62.0 (10.6)</td>
<td>46–74</td>
</tr>
<tr>
<td>Patient’s sex (male/female)</td>
<td>3/6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner’s age (years)</td>
<td></td>
<td>62.8 (12.1)</td>
<td>46–79</td>
</tr>
<tr>
<td>Partner’s sex (male/female)</td>
<td>6/3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time together as partners (years)</td>
<td></td>
<td>41.9 (9.6)</td>
<td>27–53</td>
</tr>
<tr>
<td>Married/cohabiting with children living at home</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting without children living at home</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since AF diagnosis (years)</td>
<td></td>
<td>9.1 (6.9)</td>
<td>2–20</td>
</tr>
</tbody>
</table>

SD = standard deviation
Data Collection

Systematic Literature Search (I)

Computerized searches for eligible studies were performed in PubMed, CINAHL, and PsycINFO. Search terms and databases were selected in collaboration with a university librarian specialized in computerized literature searches as well as with research specialists within the area. The search strategy comprised searches using thesaurus terms, which is a specific controlled vocabulary applicable in the databases (i.e., CINAHL Headings, Medical Subject Headings [MeSH], or PsycINFO thesaurus). The controlled vocabulary is made up of words that describe the content of an article (usually assigned 5–15 thesaurus terms). The search strategy, when utilizing thesaurus terms, narrows the search towards studies that are assigned, or indexed, with the specific thesaurus term. In addition, the search strategy utilized free-text searching, in which the specific search term may be found “freely” within the record entry, e.g., title, abstract, and/or subject (note: the default fields for unqualified searches differ between databases). In order to be eligible for analysis, the article had to meet criteria of addressing either (i) couples’ experiences within the partner relationship following cardiac disease or (ii) patients’ and/or spouses’ experiences within the partner relationship following cardiac disease. Articles focusing on experiences during the pre-/in-hospital phase were not applicable for inclusion. Further, articles explicitly addressing issues related to how social support and/or coping are mediated were not applicable for inclusion, nor were articles addressing quality of life. Moreover, the articles had to be original papers written in English subjected to peer review, ethically approved, and published between 1999 and 2009. Following the removal of duplicates and exclusion based on title, the computerized search yielded 73 articles for further review and quality assessment. The subsequent review excluded 51 articles based on lack of specific focus on the partner relationship or the interaction between patient and partners. Additionally, 4 articles were excluded based on quality assessment, leaving 18 articles from the
computerized search eligible for analysis. In addition to the computerized search, reference tables of the 18 articles were explored for potential papers that may have been left out in the computerized search. The screening of reference tables yielded an additional two articles eligible for analysis following quality assessment, leaving 20 articles subjected to analysis.

Quality Assessment of Eligible Studies

Studies that corresponded with the aim and inclusion criteria for the review (n = 24) were assessed for quality following the criteria outlined in the Joanna Briggs Institute (JBI) Reviewers’ Manual: 2008 Edition (JBI, 2008). Studies with a qualitative design were assessed using the JBI Critical Appraisal Checklist for Interpretive & Critical Research. The instrument focuses on methodology, representation of the data, and interpretation of the results. The instrument contains 10 questions/statements (e.g., congruity between the research methodology and the research question or objectives and congruity between the research methodology and the methods used to collect data), which can be responded to with “yes,” “no,” or “unclear.” The responses were then converted into points with “yes” yielding 1 point and “no” or “unclear” yielding 0 points. For a study to be subjected to analysis, a minimum of 60% (i.e., a minimum of six “yes” responses) was required (Willman, Stoltz, & Bahtsevani, 2006). Studies with a quantitative design were assessed using the JBI Critical Appraisal Checklist for Descriptive/Case Series Studies. The instrument contains nine questions/statements that focus on methodological rigor, such as the identification of confounding factors and how these are dealt with. Moreover, it focuses on whether outcomes were measured in a reliable manner (i.e., applied instruments have proven validity and reliability) and whether appropriate statistical methods were used. The questions may be responded to with “yes,” “no,” or “unclear” with responses converted into points: “yes” yielded 1 point, and “no” or “unclear” yielded 0 points. For a study to be subjected to analysis, a minimum of 67% (i.e., a minimum of six “yes” responses) was required. The quality
assessment was performed by the first, second, and fourth authors of study I.

**Qualitative Data (II and IV)**

**Interviews – Classical Grounded Theory (II)**

In total, 16 interviews with 12 couples were carried out and lasted between 22 and 55 minutes, yielding 8 hours and 35 minutes of transcribed data. Follow-up interviews were made with two patients and two partners separately. All interviews were conducted by the first author of the study. Initially, the interviews focused upon open-ended questions, such as, “Can you tell me how you experience living with AF?” and “How has living with AF affected your partner relationship and daily life together?” Reflective follow-up questions were utilized to grasp the dynamics within the partner relationship (Glaser, 1978, 1998), such as, “What do you feel about what your spouse just said?” Throughout the data collection process, field notes were written from conversations that took place outside the interview as well as memos that constituted reflections of what the couples said. This is consistent with classical grounded theory (GT), which suggests that “all is data” (Glaser, 1998, p. 8). A distinct feature within GT is that data collection and analysis are not performed separately but, rather, occur simultaneously with theoretical sampling functioning as a guide of what data to collect next (Glaser, 1998). From this, the interview questions were altered during the course of data collection. This will be further elaborated in the analysis section below.

**Interviews – Hermeneutics (IV)**

In total, nine interviews were carried out and lasted between 34 and 75 minutes each. In total, 8 hours and 30 minutes of interview data were collected. The interviews were guided by a few broad questions, such as, “Can you tell me how you experience living with AF?”, “How has living with AF affected your daily life together?”, “What is different today compared to the time before AF?”, and “What concerns you the
Circular questions were asked to grasp each couple’s mutual story, such as, “What do you think about what your partner just said?” and “Do you feel the same regarding what your partner just said?”

**Quantitative Data (III)**

The following instruments were used for data collection on perceived health and emotional distress.

*The Medical Outcomes Short Form Health Status Survey* (SF-36) is a generic health instrument that measures functional health and well-being. The instrument covers 36 items across eight subscales: physical functioning (PF), role limitations due to physical problems (RP), bodily pain (BP) and general health (GH), social functioning (SF), mental health (MH), role limitations due to emotional problems (RE), and vitality (VT). In addition, the SF-36 generates a physical component score (PCS) and a mental component score (MCS) aggregated from the subscales. The PCS is aggregated by physical functioning, role limitations due to physical problem, bodily pain, and general health. The component score for the MCS is aggregated by social functioning, mental health, role limitations due to emotional problems, and vitality (Ware, 2004). Answers are transformed into scale points ranging between 0 and 100. Thus, each individual subscale as well as the component scores can attain values between 0 and 100 where a higher value indicates higher self-perceived health.

For the purpose of study III, perceived health in patients and spouses was constituted by PCS and MCS as well as the two subscales of GH (comprising five items with a five-point scale ranging from 1 to 5) and VT (comprising four items with a six-point scale ranging from 1 to 6). The rationale behind selecting the GH subscale (with items such as, “I seem to get sick a little easier than other people,” “I am as healthy as anybody I know,” “I expect my health to get worse,” and “My health is excellent”) and the VT subscale (with items such as, “level of energy,” “tiredness,” and “feeling worn out”) is embedded in the notion
that they correlate significantly with both the PCS and MCS (Taft, Karlsson, & Sullivan, 2004; Ware, 2004). The SF-36 has been shown to have adequate validity and reliability and has been translated into Swedish (Taft et al., 2004). Regarding study III, internal consistency measured with Cronbach’s alpha was 0.80 for GH, 0.86 for VT, 0.92 for the PCS, and 0.91 for the MCS. Hereafter, PCS is denoted as physical health, and MCS is denoted as mental health, unless otherwise stated.

The Hospital Anxiety and Depression Scale (HADS) is an instrument that measures self-reported anxiety and symptoms of depression, as perceived during the last week (Zigmond & Snaith, 1983). The questionnaire consists of 14 items, in which seven measure anxiety (HADS-A) and seven measure symptoms of depression (HADS-D). Each item has a 4-point scale ranging from 0 to 3. Reversed items are rescored, and total scores are calculated for anxiety and symptoms of depression ranging from 0 to 21. Scores of ≤7 are regarded as no anxiety or symptoms of depression, scores of 8–10 are considered as being suggestive of anxiety or symptoms of depression, and scores of ≥11 indicate probable anxiety or symptoms of depression (Snaith, 2003). The HADS is considered to have adequate validity and reliability and has been translated into Swedish (Lisspers, Nygren, & Soderman, 1997). In the present study, internal consistency measured with Cronbach’s alpha was 0.84 for HADS-A and 0.82 for HADS-D.

Data Analysis

Integrative Analysis (I)

Included studies were analyzed using an inductive approach with the aim of identifying how the partner relationship is affected following cardiac disease in one of the spouses. The included studies had various perspectives, i.e., patient, partner, or couple’s perspectives. However, only data that described and reported aspects on the couple’s
interaction, effects on daily life, and their relationship were extracted and subjected to analysis. The data analysis was inspired by the integrative approach as described by Whittemore and Knafl (2005), in which the findings were integrated into a meaningful whole, not just a pure listing of the results from each study. Data were extracted from the articles on sample characteristics, method, and results and subsequently entered into a matrix chart. Units in the article’s result section, which corresponded to the aim, were entered into a separate chart and subsequently grouped together based on similarities and differences. The grouping led to categories that described couples’ experiences within the partner relationship following cardiac disease or patients' and/or spouses' experiences within the partner relationship following cardiac disease. Corresponding categories were grouped together and subsequently abstracted into themes. Through the analysis, five descriptive themes emerged.

**Classical Grounded Theory (II)**

As mentioned previously, data collection and analysis are not performed separately within GT; rather, they occur simultaneously. Therefore, each interview was transcribed immediately after it was performed and analyzed together with field notes prior to the next interview. Thus, theoretical sampling functions as a guide of what data to collect next (Glaser, 1998). Through open coding, which is the foundation in category generation, questions were pointed towards the data; “What are these data a study of?”, “What category does this data implicate?”, “What is actually happening in the data?”, “What is the main concern for the couples?”, and “What accounts for the continual resolving of this concern” (Glaser, 1978; Glaser & Holton, 2004). Open coding directs and guides theoretical sampling and is necessary to maintain theoretical sensitive when analyzing, collecting, and coding the data (Glaser, 1998). Throughout the study, questions were developed based on the ongoing analysis, such as, “How do you share concerns and uncertainty about AF with each other?” The codes were analyzed, and similar meanings in the codes were grouped into
categories. Codes and categories were constantly compared with newly generated codes and categories throughout the course of the study. During this process, the main concern and core category emerged. The core category explains how the main concern was continually resolved (Glaser & Holton, 2004). Following this, selective coding was initiated in which data collection and coding were delimited to categories related to the core category, i.e., interviews focused on managing uncertainty through explicit and implicit sharing. Saturation was reached when the latest collected data did not contribute further to the generation process. During the entire analytical process, memos were written in text and figures related to the categories. Writing memos is fundamental in GT and is the “theorizing write-up” of ideas and possible relationships between codes (Glaser, 1998). Through theoretical coding, memos were hand-sorted, and relationships between categories and the core category emerged. Sorting of the memos is fundamental since it is a conceptual sorting through which the integration of the theory emerges. Essentially, “theoretical codes implicitly conceptualize how the substantive codes will relate to each other as interrelated, multivariate hypotheses in accounting for resolving the main concern” (Glaser, 1998, p. 163). In GT, there are several theoretical coding families, and during the analysis, typology emerged as the most suitable theoretical code. Thus, a theoretical model – in this case, a typology – was used to explain the theory. Furthermore, in accordance with GT, a literature review was performed and added as another source of data to refine the theory (Glaser, 1998).

**Actor–Partner Interdependence Model (III)**

The Actor–Partner Interdependence Model (APIM) is a model of dyadic relationships incorporating interdependence in two-person relationships (Cook & Kenny, 2005). Through the APIM, it is possible to study the influence of a person’s predictor variable on his/her own outcome variable (denoted as an actor effect) as well as on the outcome variable of the partner (denoted as a partner effect) (Kenny, Kashy, & Cook, 2006; Kenny & Ledermann, 2010). Within the APIM, dyad
members are considered to be distinguishable if there is a meaningful factor that can be used to order the two persons (Kenny et al., 2006) – for example, a person with illness and a person without. Thus, for study III, the dyad members were considered to be distinguishable based on AF diagnosis. Following the aim in study III, it was hypothesized that emotional distress in terms of anxiety and symptoms of depression was associated with perceived health. A graphical illustration of the APIM, as applied in study III, is seen in Figure 1.

![Figure 1. The Actor–Partner Interdependence Model as applied in study III.](image)

More specifically, the stipulated hypotheses were as follows: (i) **actor effects** are present where patients’ and spouses’ emotional distress is associated with their own perceived health, and (ii) **partner effects** are present where patients’ and spouses’ emotional distress is associated with their partners’ perceived health. As specified above, emotional distress was measured through the HADS and perceived health through the SF-36 subscales General Health and Vitality as well as the component scores of the PCS and MCS. Thus, in total, eight APIM models were set up. Analyses of associations were conducted at a dyad level through the APIM (Cook & Kenny, 2005; Kenny et al., 2006) using structural equation modeling for distinguishable dyads.

**APIM using Structural Equation Modeling**

Structural equation modeling (SEM) is a method that allows for the evaluation of full models (such as the APIM), which brings a higher-level perspective to the analysis (Kline, 2011). Accordingly, SEM
consists of two important features: (i) the associations under study are represented by a series of regression equations, and (ii) the associations can be modeled pictorially to grasp the theoretical conceptualization (Byrne, 2010), such as the APIM. The most common estimation in SEM is maximum likelihood (ML) estimation, which solves the set of equations in a model by using an iterative solution (Kenny et al., 2006; Kline, 2011). This means that the estimates are conducted by several repeated cycles of calculations in order to find the best solution. A fundamental assumption when using ML is that the data should be normally distributed – an assumption that was violated in the dataset for study III. To overcome this, the eight APIM models were performed using robust maximum likelihood estimation, which takes non-normality into account by using robust standard errors (Kline, 2011). Prior to the analysis, patient and spouse predictor scores were grand-mean centered (i.e., subtracting the mean), following the recommendations of Kenny et al. (2006). The amounts of missing data for the HADS and the SF-36 were low (0.6%). Missing values were replaced with item means for patients and partners, respectively. The APIM analysis was conducted in Mplus Version 7.3 for Mac OS (Muthén & Muthén, Los Angeles, CA, USA). The level of statistical significance was set at 5% (p < 0.05).

Comparisons and Correlations
Comparisons and correlations of scores between patients and spouses were conducted using Wilcoxon Signed Rank test and Spearman’s Rho correlation (Altman, 1991). These statistical analyses were conducted using SPSS version 21 for Windows (IBM Corp, Armonk, NY, USA). The level of statistical significance was set at 5% (p < 0.05).

Hermeneutics (IV)
The data analysis was based on the assumption that beliefs are embedded in the stories and conversations that we exchange with one another (Wright & Bell, 2009). Given this, the hermeneutic philosophy of Gadamer (1994) was used to understand illness beliefs in couples
living with AF. Within Gadamerian hermeneutics, understanding emerges from a circular relationship where “we must understand the whole in terms of the detail and the detail in terms of the whole” (Gadamer, 1994, p. 291). Gadamer describe this process, called the hermeneutical circle, in which the interpreter is projecting, i.e., one project meaning for the text as a whole as soon as some initial meaning emerges in the text. The initial meaning that emerges does so as a consequence as the text is read with some particular expectation that, throughout the process, is revised. Thus, interpretation starts with preconceptions that are projected and continually replaced or revised. However, the preconceptions that are projected are not to be illogical to the subject in matter – i.e., the projected conceptions must be relevant and not arbitrary. The constant process of new projection is constituted by the movement of understanding and interpretation. Embedded in this is that understanding is not possible without the notion of preconceptions, in terms of preunderstanding or prejudices, which are described by Gadamer as historical horizons that are in continual movement as we constantly have to test our prejudice. Thus, understanding is the fusion of horizons where the interpreter incorporates the text with his or her own preconception or prejudice, i.e., “in the process of understanding, a real fusing of horizons occurs – which means that, as the historical horizon is projected, it is simultaneously superseded” (Gadamer, 1994 p. 307). As Gadamerian hermeneutics does not provide an explicit framework for analysis, the analysis followed the four steps for gaining understanding through dialogue with the text as described by Fleming, Gaidys, and Robb (2003). The four steps are rooted in the hermeneutics as described by Gadamer. The steps involve (1) reading all interview texts as gaining understanding of the whole text, (2) investigating sections and sentences to expose meaning of the subject in matter, (3) relating the sections and sentences to the whole text and the whole text back to the sections and sentences, and (4) identifying passages that seem representative of the shared understandings between the researchers and participants.
Initially, the transcribed interviews were read to gain an understanding of the couple’s stories. Secondly, sections in the transcribed interviews consisting of possible beliefs were highlighted and given a brief content description. Following this, the content descriptions for each interview were individually summarized with the intent to capture what was happening in the interview. Thirdly, in line with the hermeneutic circle, the content descriptions were seen as the parts and the interview text as the whole in the hermeneutic circle. Additionally, the individual summaries were seen as parts of the overall interview material. In the final step, the researcher’s prejudice, consisting of experience of clinical work with patients with AF as well as previously having studied couples with AF, constituted a historical horizon that was projected towards the text. Beliefs were interpreted to be found in their dialogue; i.e., a belief could be expressed individually but affirmed by the others in their dialogue. Moreover, mutual beliefs were interpreted from expressions of we-ness in the couple. The analysis resulted in three core and six secondary beliefs. A core belief can be described as being fundamental to how we approach the world and how we live; it forms our identity, and we live as if it were true (Wright & Bell, 2009). Core beliefs are deeply rooted and cannot be easily changed; they are powerful and have a profound influence on affective response and family functioning. The secondary beliefs were derived from the core beliefs and are all related to living with AF and are more likely to be able to change.

Ethical Considerations

Encounters between patients and caregivers within clinical care settings often indicate that the patient is in a position of dependence towards the caregiver. Usually, there is an asymmetry of information that generally works to the benefit of the care provider. Thus, when recruiting patients and partners inside a clinical care setting for participation in studies, the patient and partner are to be assumed to be in a position of dependence to the recruiting health-care personnel. Therefore, recruitment
procedures of patients in clinical setting require ethical considerations (Jairath, Ulrich, & Ley, 2005).

As such, participation in the studies was thoroughly based upon informed consent and couples’ willingness to participate (Council for International Organizations of Medical Sciences [CIOMS], 2002; Frye et al., 2009). Initially, patients were provided with oral and written information regarding the aim of the study, procedure for data collection, and voluntary participation as well as that they could withdraw from participation at any time without having to disclose a reason why (CIOMS, 2002; Jairath, Ulrich, & Ley, 2005). If patients gave consent to participate, partners were asked to participate and given the same information. Thus, a couple’s participation was exclusively dependent on initial consent from the patient. Moreover, participants were informed and guaranteed that their participation was guarded by confidentiality, indicating that research data were safely stored and their individual identities protected. Participants were also informed that their individual identities would be protected when reporting research findings. Interview data as well as data from questionnaires were kept in a secure locker. As the interviews could raise questions and issues that previously had not been disclosed between the partners, couples were informed that they could terminate and withdraw from the interview at any time. In addition, they were informed and advised to contact the researcher or their physician if needed after the interview.

Following the deficiency of thoroughly substantiated knowledge of AF’s implications for a couple’s partner relationship and daily life, the individual studies were deemed appropriate both from the perspective of generating knowledge and to potentially substantiate future interventions. Thus, the potential clinical benefit for afflicted couples was deemed reasonable in the light of potential risks (CIOMS, 2002). The individual studies (II–IV) received ethical approval from the Regional Ethical Review Board, Linköping, Sweden (reference no. M8-09).
Findings

Implications for Couples Relationship and Daily Life Following Cardiac Disease in One of the Spouses (I)

Couples’ relationships and daily living are affected in several ways when one of the partners is afflicted with a cardiac disease. Analysis of the included studies generated five descriptive themes of how the partner relationship is affected following cardiac disease. Overprotection occurs when couples have differences of opinion on what could be regarded as a viable activity; the partner express worry that the patient should not perform physically as this might trigger the heart. This expression of worry is understood as nagging and overprotection by the patient. Even though the patient could recognize the good intention, he or she still felt controlled and as is he or she was on probation. Communication deficiency within the couples occurs as a result of the couple’s perception that talking and sharing of emotions may result in elevated emotional distress in the other. Therefore, both patients and partners occasionally withhold their emotions as a means of protecting each other. Contrary to the intended protection, disengagement leads to increased levels of emotional distress in some patients. Sexual concerns in couples emerged from fear that sexual activities may cause the ICD (implantable cardio defibrillator) to trigger or that it would be stressful to the heart, which could induce an angina attack or a heart attack. Most couples experienced implications concerning their sexual life following cardiac disease, though to varying degrees. Some couples reported fewer implications in terms of no limitations on or concerns about resuming sexual activity; other couples reported more prolonged effects. Changes in domestic roles were noticeable as most couples experienced a shift in roles and responsibilities within the partner relationship, where spouses had to take on additional tasks or do tasks for the patients. Partners took on tasks and responsibilities that previously belonged to the patient;
likewise, patients did not perform tasks that they had done previously. The changes caused frustration in both patients and spouses as they limited their lives in terms of both having to give up things. Adjustment to illness was seen as incorporating the illness into their everyday lives through adopting new healthy practices and changes of diet and routines. For some partners, this was met with feelings of solidarity, but for others, it was a source of stress. Moreover, it included changes of joint activities and hobbies as well regaining balance in their new life. Some couples experienced that the illness had brought them closer together as they discovered new meaning and reconnected with each other.
Managing Uncertainty in Couples Living with AF (II)

Couples living with AF experienced uncertainty as a common main concern. This uncertainty was rooted in causation of AF and apprehension about AF episodes with the former referring to the disease per se – i.e., couples had a deficiency of knowledge regarding what AF is and/or what underlying factors contribute to the development of AF. Apprehension about AF episodes refers to the unpredictability of knowing if, when, and why symptoms and/or AF episodes may occur. The theory of Managing Uncertainty emerged in the analysis as the continual resolving of the main concern within the partner relationship through the strategies of explicit (mutual collaboration and finding resemblance) and implicit sharing (keeping distance and tacit understanding). Time since diagnosis and elapsed time being symptom-free were factors influencing afflicted couples’ shifting between implicit and explicit sharing.

Explicit Sharing for Managing Uncertainty

Explicit sharing denoted that couples shared feelings and thoughts with each other related to AF, using verbal actions such as asking, telling, or discussing. Mutual collaboration and finding resemblance were strategies used by couples that constitute a direct interaction between the spouses. Therefore, sharing was expressed explicitly. In Mutual Collaboration, the couple openly discussed concerns related to AF such as when to seek medical care or travelling. Most couples did not directly refrain from traveling abroad, though they expressed a feeling of being more reluctant about traveling as AF episodes occurred more frequently. Couples often met this uncertainty with sharing and discussion to plan and arrange a trip. Often, they had informed themselves regarding local surrounding hospitals and medical centers if a need for care should become necessary. This planning was not seen as stressful or restrictive but, rather, as an adjustment to their life situation and a way to manage their uncertainty. In Finding Resemblance, couples tended to “talk around” AF and reflect their
thoughts and uncertainty onto others, such as friends or coworkers, who were afflicted with AF or other cardiac diseases. In the event of traveling, couples related their uncertainty that something may occur during a flight to previous flight experiences and onto other people afflicted with cardiac disease. As such, when others with cardiac illness were still able to travel, it eased the uncertainty. Imbedded in finding resemblance is the desire to “get well” or “get treated.” With limited knowledge of what factors constitute AF as well as getting discrepant information from medical professionals regarding treatment options, their desire to become well served as a grounded uncertainty. This uncertainty was enhanced by seeing others who had been successfully treated with catheter ablation or cardioversion. They reflected reasons they had not been successfully treated through current treatment strategies or why they had not yet been offered alternative treatment options.

**Implicit Sharing for Managing Uncertainty**

Implicit sharing denoted that couples do not explicitly share feelings and thoughts with each other related to AF. Within this, couples indirectly interacted with each other through the strategies of keeping distance and tacit understanding, in which sharing is expressed implicitly. In *Keeping Distance*, patients did not want or wish to distress each other. They believed their spouses were already worried and should not be further distressed. The partners had a perception that asking and sharing may come across as nagging and overprotection; therefore, they choose not to nag and query the patient about thoughts and feelings related to AF. As both spouses considered asking about and sharing emotions and feelings related to AF to be a source of additional and enhanced distress, they tended to distance themselves and refrained from explicit sharing of AF-related issues. Likewise, when initiation of explicit sharing was met with negligence, couples tended to move towards distancing in terms of implicit sharing. In *Tacit Understanding*, couples had a need for *not* having to talk about all things. The couples had lived together for many years and had
developed an understanding with each other. From this, they could sense each other’s feelings and concerns and did not need to explicitly share with each other to manage their uncertainty. Inherent in this strategy was also that some couples believed that it is unhealthy to dwell on and think too much about the disease. This does not suggest that couples neglected either the disease or each other. In fact, the strategy of tacit understanding proposed that they were aware and could sense each other’s feelings and concerns and, therefore, were able to sense how the other spouse felt, both good and bad.

**Shifting Between the Sharing Strategies**

Couples were not limited to only using one of the strategies; rather, they could shift between the different strategies. As relationships are non-static, which implies that they change over time, the same applies to the couples: they could shift and alter between the sharing strategies. The shifts between sharing strategies were not necessarily done intentionally; rather, couples tended to move towards implicit sharing as more time elapsed from an AF episode or if explicit sharing was met by negligence from the other spouse. Moreover, as more time progressed since diagnosis, couples tended to utilize implicit sharing in terms of tacit understanding, in which the presence of AF became more ordinary in their lives. However, if the frequency of AF episodes increased, couples could again shift towards explicit sharing.
Actor Effects and Partner Effects in Couples Living with AF (III)

There were no significant differences between patients and spouses regarding anxiety or symptoms of depression. Perceived health, in terms of general health, vitality, physical health, and mental health, differed significantly for patients and spouses, with patients reporting significantly lower levels of perceived health than their spouses.

Symptoms of depression in patients were significantly correlated with their spouses’ symptoms of depression, anxiety, vitality, and mental health, indicating that higher levels of symptoms of depression in patients were associated with higher levels of symptoms of depression and anxiety and lower levels of vitality and mental health in their spouses. Patients’ level of anxiety was not significantly correlated with their spouses’ anxiety, symptoms of depression, or perceived health.

Spouses’ level of anxiety correlated significantly with patients’ symptoms of depression but not with perceived health, indicating that higher levels of anxiety in spouses were associated with higher levels of symptoms of depression in patients. Spouses’ symptoms of depression correlated significantly with the patients’ symptoms of depression and perceived health, indicating that higher levels of symptoms of depression in spouses was associated with higher levels of symptoms of depression as well as lower levels of perceived health in patients.

Associations of Emotional Distress and Perceived Health

The APIM analysis revealed that emotional distress is associated with perceived health – mostly through actor effects, where patients and partners affect themselves (Table 3). The postulated hypotheses were verified to some extent with 14 actor effects (of 16 possible) and 3 partner effects (of 16 possible) identified.
Table 3. Actor and Partner Effects

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th></th>
<th>Spouse</th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>Actor Effect</td>
<td>Partner Effect</td>
<td>Actor Effect</td>
<td>Partner Effect</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Health</td>
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<td>.321</td>
<td>&lt;.001</td>
<td>.065</td>
</tr>
<tr>
<td>Vitality</td>
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<td>&lt;.001</td>
<td>.151</td>
</tr>
<tr>
<td>Physical Health</td>
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<td>.548</td>
<td>.042</td>
<td>.080</td>
</tr>
<tr>
<td>Mental Health</td>
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<td>&lt;.001</td>
<td>.338</td>
</tr>
<tr>
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<td></td>
<td></td>
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<td>&lt;.001</td>
<td>.029</td>
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<td>.248</td>
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</tbody>
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**Anxiety on Perceived Health**

The APIM for anxiety in perceived health found significant patient–actor effects and spouse–actor effects in all models, with the exception of physical health for the patient–actor effect (Table 3). All significant actor effects showed negative associations, indicating that higher levels of anxiety were associated with lower levels of perceived health. No significant partner effects of anxiety on perceived health were found. Figure 2 illustrate the APIM for anxiety and general health.

![Diagram of relationships between anxiety and general health](image)

**Figure 2.** The actor and partner effects of anxiety on general health.

b=unstandardized regression coefficient.
**Symptoms of Depression on Perceived Health**

The APIM for symptoms of depression in perceived health found *patient–actor effects* and *spouse–actor effects* in all models with the exception of physical health for spouse actor effects (Table 3). All significant actor effects showed negative associations, indicating that higher levels of symptoms of depression were associated with lower levels of perceived health.

*Patient–partner effects* and *spouse–partner effects* were observed for vitality, indicating that higher levels of symptoms of depression in patients and spouses were associated with lower vitality in their partners. *Spouse–partner effects* were also identified for physical health, indicating that higher levels of a spouse’s symptoms of depression were associated with lower levels of perceived physical health in the patient. However, no significant patient–partner effect was found for physical health. No other patient– or spouse–partner effects were found for symptoms of depression in general health or mental health. Figure 3 illustrates the APIM for symptoms of depression and vitality.

![Diagram of actor and partner effects on vitality](image)

*Figure 3.* The actor and partner effects of symptoms of depression on vitality. 

$b=$unstandardized regression coefficient.
Core and Secondary Illness Beliefs in Couples Living with AF (IV)

The analysis revealed both core and secondary illness beliefs. From the core illness belief *the heart is a representation of life*, two secondary illness beliefs were derived: AF is a threat to life, and AF can and must be explained. Further, from the core illness belief *change is an integral part of life*, two secondary illness beliefs were derived: AF is a disruption in our life, and AF shall not interfere with our life. Finally, from the core illness belief *adaptation is fundamental in life*, two secondary illness beliefs were derived: AF entails adjustment in daily life, and AF entails confidence and adherence in professional care. However, the identified illness beliefs should be regarded not as a complete description of inherent illness beliefs in the couples but, rather, as a part of possible existing illness beliefs.

In the core belief *the heart is a representation of life*, couples with AF expressed that the heart is a symbol of life itself, and, when illness strikes the heart, the very foundation of life is put to the test. AF affects the symbolic representation of life and ultimately constitutes a threat to life. As AF was expressed as a threat to life, it entailed a need for protection. When couples with AF withhold feelings of worry or uncertainty from each other, this can be understood as springing from a thoughtful intention to protect the other spouse. Thus, when couples face AF, it acts as a threat to the representation of life and, therefore, has to be explained in order to be comprehensible. As the heart is seen as an essential element and representation of life, couples describe reasons and explanations – e.g., heredity, previous lifestyle or activities – to find a trajectory of why they are afflicted with AF as well as what triggers AF episodes. When it is expressed that AF is caused by hereditary factors, couples detach themselves from liability in the trajectory because there was nothing they could have done to prevent or avoid AF. On the other hand, couples sometimes attach factors within the couple, such as lifestyle factors and previous life events, as
causative factors for the trajectory of AF. This can be understood as indicating that, when the reason for AF is within the couple, understanding and making sense of AF is imminent.

In the core belief change is an integral part of life, becoming afflicted with AF enacts a shift from a non-ill-life-place to an ill-life-place. As this shift is not done voluntarily, AF can be seen as an uninvited occurrence in the couple’s lives. However, this was not seen as a deviation from the natural course of life; life is full of events and occurrences that impose changes, and AF is such an event. This can be understood as meaning that change is a natural phenomenon that one cannot avoid. Prior to AF, being well was taken for granted – a view that becomes altered though AF. AF confronts the image of being well in favor of being ill, which can be understood as meaning that AF disturbs their lives in terms of altering their view of being healthy and well and not supposedly afflicted with illness. Couples express that there is no point in dwelling on AF as it has occurred regardless of what one thinks about it and that dwelling will not make AF disappear. This can be understood as meaning that sharing and dwelling would commit AF to take up too much space and interfere with their lives. Inherently, couples express that AF is always present in their lives but that one can deliberately decide on the amount of space that AF is allowed to take in their daily lives.

In the core belief adaptation is fundamental in life, one continuously adjusts in life – regardless of the reason. Adaptation is intrinsically associated with having control – which indicates that adaptation to an imposed change cannot be accomplished without the notion of having control. AF imposes a threat to the couple’s zone of certainty and control as well as bringing uncertainty and unpredictability. Within their zone, couples are safe and secure and have control of their inherent reality. Couples express that adjustment and adaptation to initiated threats is a necessity in life; they assert that threats must be managed and controlled in order to maintain or re-establish the boundaries of the
zone of certainty. In order to maintain or re-establish safety and security, couples need to adjust accordingly to establish a sense of control over AF. When couples themselves determine the boundaries of the zone – i.e., when couples deliberately adapt the boundaries of the zone based on AF – this can be understood as that couples’ adaptation serving as an instrument for enacting control over AF. On the other hand, couples can sanction others to determine the boundaries of the zone, which may work favorably in terms of adjusting accordingly and having control. Through confidence and adherence to prescribed medical regimes, couples can control AF, even though the feature of control is induced by someone else. Couples express that having trust in health care professionals is vital as AF is a condition that must be thoroughly managed. Medicines and health care professionals are vital because they provide what is necessary to stay alive and to confine the potential risk of stroke.
Discussion

Reflections on the Findings

The overall aim of this thesis was to describe and explore how the partner relationship of patient–partner dyads was affected following cardiac disease and, in particular, AF in one of the spouses. To achieve this aim, four individual studies with various designs were conducted to view the patient–partner dyad from different aspects. Overall, it was found throughout the studies that the couple, as an interdependent feedback system, affected and influenced each other (I–IV) on aspects such as making sense of AF (I, II, IV), responding to AF (I, II, IV), and mutually incorporating and dealing with AF in their daily life (I, II, IV). Combined, the results (I–IV) may serve as an indication for applying an FSN approach in clinical practice as well as a construct for future research interventions. The findings will be related to previous research and theoretical aspects on couples living with chronic illness as well as the theoretical aspects underlying FSN.

Couples Making Sense of AF

The results imply that the affliction of AF brings uncertainty and unpredictability into the couple’s life; AF challenges their current existence by inflicting something that is unknown and excursive to them. The uncertainty is rooted in the notion that they do not know what AF is but also in the unpredictability of relapsing AF episodes. According to Mishel (1999), uncertainty in chronic illness becomes prevalent because of factors such as unpredictable symptoms, persistent questions about reoccurrence or aggravation of illness, and an unknown future. Consequently, couples try to find reasons for why AF has occurred and what possible factors contribute to the initiation of AF episodes. Previous studies on AF have also found that patients and partners experience uncertainty related to diagnosis as well as apprehension regarding unpredictable AF episodes whereby they try to
find meaning and explainable attributes for their symptoms and diagnosis (Ekblad et al., 2014; McCabe, Schumacher, et al., 2011). This feature of trying to make sense of AF is rooted in an attempt to explain and organize an experience (Rolland, 2012; Wright & Bell, 2009). When an experience or disturbance is not obvious or has a form that cannot be understood or explained, the disturbance is met with concealment (Bateson, 1998) and/or aggravated uncertainty (Mishel, 1999). However, when an experience can be organized and explained, it promotes a sense of mastery (Rolland, 1998, 2012), whereas low understanding and appreciation of AF contributes to psychological distress (Foxwell, Morley, & Frizelle, 2013; McCabe & Barnason, 2012). Thus, couples try to make sense of this uncertainty by searching for causative factors to explain the trajectory of AF, such as heredity and previous lifestyle/activities, and what factors that promote or initiate the relapsing of AF episodes, but also through finding resemblance in others, such as friends and co-workers, with cardiac illness. Similar findings have been described by Mishel (1999), who found that management of illness uncertainty, characterized by episodic onset and duration, involves the identification of markers and triggers for the illness occurrence. Embedded in this is the notion of letting AF becoming a part of their daily lives and relationships. By means of accepting and making sense of AF, couples create a sense of restricting the implications of AF and letting AF to become normalized into their everyday lives. Similar things have been found in other relapsing chronic illnesses, such as MS, where couples normalized the presence of MS by accepting it in their planning and thinking, thereby minimizing its influence in their lives (Boland et al., 2012). Thus, uncertainty prevails as long as a cognitive schema for recurrent illness events has not been developed that structures the meaning of illness-related events (Mishel, 1988). However, when couples can attach meaning related to the cognitive schema of symptom pattern (e.g., intensity, frequency, and duration), event familiarity (e.g., the degree to which the situation contains recognized cues) and event congruence (consistency between what is expected and what is experienced in
illness-related events), this may create less uncertainty (Mishel, 1988). Similar concepts have been suggested by Thoits (1986), who expressed that, if situations can be altered cognitively in terms of reinterpretation of existing circumstances, they may seem less threatening and, therefore, elicit less undesirable feelings (e.g., couples with AF are finding resemblance in others with cardiac illness). Accordingly, this technique may be particularly appropriate when the situation is uncontrollable or when the individual lacks the power to escape or alter the situation.

However, the results indicate that couples still experience uncertainty regardless of having identified causative factors for the trajectory of AF (e.g., certain foods or activities) or the utilization of approaches to acclimatize AF in their daily lives (e.g., adhering to prescribed treatment or finding resemblance in others, etc.). Thus, the erratic and relapsing nature of AF generates an ambiguity in couples that is not easily resolved. Possibly, the facet of experiencing lasting or prolonged uncertainty in AF lays in the nature of the illness being located in the heart. Throughout time, the heart has been displayed as a symbol in an array of contexts, such as literature, music, art, and religion. It is also displayed as an icon for love, joy, and grief but also as a representation of the essence of humanity and the vital organ of the body (Perloff, 2010). Thus, the symbolic prominence attached to the heart implies that being faced with AF ultimately constitutes that life per se is threatened and not as certain as prior to AF.

**Couples’ Mutual Response to AF**

Structural determinism states that a systems response to a disturbance (e.g., AF) is dependent on the structure of the system, in which the structure has evolved from past interactions with the environment – i.e., structural coupling – which leads to structural congruence (Maturana & Varela, 1992). Accordingly, a structure-determined system may – when faced with a disturbance – either undergo a change of structure or disintegrate (Maturana, 1978). In other words, the couple may undergo structural changes in which they adapt to the situation, or they may
disintegrate in terms of dissolving the system – e.g., divorce. When couples lack experience and knowledge regarding AF, they also lack viable explanations and responses – which ultimately brings uncertainty into the couple’s life. However, the couples have previously, throughout the course of their lives and relationships, experienced disturbances – or changes – that have brought uncertainty into their everyday lives. Therefore, the structure-determined system (i.e., the couple) has an in-built structure that directs that AF can and must be responded to. Following this, the encounter and interaction between the couple and AF, in terms of structural coupling (e.g., mutual identification of triggers of AF), promotes structural changes that, in turn, evolve responses towards the AF (e.g., couple’s avoidance of certain foods or activities). In other words, the structural changes that the couples undergo through structural coupling with its environment may be seen as mutual adaptive responses (Proulx, 2008) to make sense of AF and deal with AF in their daily lives.

As such, recurrent interactions between the system and the disturbance will result in a history of mutual congruent structural changes in which the system adapts (Proulx, 2008). Recursive feedback is a central feature in cybernetics, and, as such, homeostatic regulation involves the interaction among the entities that comprise a living system as well as between the system and the surrounding environment (Lyon, 2004). As a couple can be seen as an organized system that is self-regulating (Bateson, 1998; Maturana & Varela, 1992), when something disturbs the system, it adjusts to maintain balance – it strives toward homeostasis through mutual response and adaptation. However, this does not necessarily imply that couples actively work or seek to get back to a pre-AF state; rather, it is a work of reaching stability in their new situation (e.g., adjustment of joint activities or adjustment in household duties). Similar things have been described by Sharpe and Curran (2006), who express that adjustment may be described as a response to a change in the environment (e.g., AF) that allows an organism (e.g., the couple) to become more suitably adapted to that change. Thus, successful adjustment should not be viewed in terms of
having to get back to pre-illness functioning as some illnesses necessitate endings of certain activities (Sharpe & Curran, 2006). In terms of AF, the results found that some couples could no longer perform certain physical activities or had to refrain from some social arrangements. This should not be regarded as a maladaptive adjustment, then; rather, it should be viewed in terms of adjustment suitable for the change. In accordance with structural coupling, the interactions within the couple, such as finding resemblance with others, planning activities accordingly, or not letting AF to take too much space in their lives, make way for finding stability in their new state. Similar findings have been reported in couples living with MS; couples were able to recalibrate and continue to do things that were meaningful to them through adjustment of expectations to meet the reality of their lives and to prioritize challenges and creatively find solutions together (Starks, Morris, Yorkston, Gray, & Johnson, 2010).

The results seem to indicate that couples may experience and respond differently to the same disturbance, which lends support to the notion of structure-determined systems, as described by Maturana and Varela (1992). From this, it is therefore plausible to postulate that the self-regulatory process, in terms of mutual response and mutual strategies, within the couples is governed by the co-evolved reality and structure of the couple. As such, couples’ interdependent management of AF may be seen to be a self-regulatory process towards homeostasis in which the spouses’ interaction and co-creation of reality elicit a mutual response towards AF.

**Couples Interdependent Management of AF**

Interdependence refers to the aspect that two individuals influence each other’s outcome through their interaction, such as when one person’s emotion, cognition, or behavior affects the emotion, cognition, or behavior of a partner (Cook & Kenny, 2005; Kelley et al., 2003). As such, the results suggest that AF is an implication in which the members of the couple mutually affect each other. The result proposes couples’ interdependence and reciprocity in terms of mutual experiences and
beliefs, mutual response, and mutual strategies, which indicate that the couples are structurally coupled (Maturana & Varela, 1992) – i.e., they co-evolve their reality through their interaction. More specifically, the results indicate that couples had to alter the previous roles and tasks, experienced changes in domestic roles, developed dyadic strategies for managing uncertainty and concerns related to AF, and they evolved mutual beliefs concerning AF. As such, the results indicate that AF may be regarded as a dyadic stressor in which the members of the couple are intertwined in co-creating their inherent reality – how they are affected by AF and how they have to deal with this. In contrast to individual stress, dyadic stress takes into account the dynamic interplay between partners (Bodenmann, 1997). Dyadic stress may be described as a stressful encounter that affects both partners directly or indirectly and triggers coping efforts in both partners. Thus, dyadic coping assumes that the interdependence and the reciprocity of the spouses, their common concerns and their mutual goals, stimulate a joint appraisal and problem-solving process (Bodenmann, 2005), which share similarities with structural determinism and structural coupling (Maturana & Varela, 1992). Both members of the couple participate in the process in order to handle or manage issues relevant to the dyad by using strategies such as joint problem solving or joint information seeking (Bodenmann, 2005). The thesis results suggest that the couples mutually adjusted activities and the boundaries of AF (joint problem solving) as well as informing themselves regarding local surrounding hospitals and medical centers or finding clues for the trajectory of AF (joint information seeking). These types of strategies may be considered to be active engagement, which is a matter of involving the partner in discussions or inquiring how the partner feels (Coyne & Smith, 1991) and are directed at trying to do something about the illness (Altschuler, 2015). From this, it may be argued that the interdependence in the couples postulates a view of AF as a *we*-illness. Previous studies have reported that, when couples view illness as a mutual concern or a *we*-awareness, they have better health prognostics (Rohrbaugh, Mehl, Shoham, Reilly, & Ewy, 2008) and are better able to adjust to changing
illness demands (Skerrett, 1998). On the other hand, the thesis results reveal some contrary aspects of we-ness where couples do not openly talk about and discuss feelings and concerns related to AF. However, concealment of feelings or not talking about AF should not necessarily be interpreted as detrimental in terms of low relationship quality or an act of repressing the illness. Rather, the results postulate that it can be seen from other aspects. First, not having to talk about everything comes from the notion that couples that have shared many years together do not necessarily need to verbally talk about things in order to communicate – understanding of the other partner’s feelings and concerns is communicated and appraised through other sources such as how one sighs or glances. In fact, it could be interpreted as the couple having high perceived partner responsiveness, in which partners have feelings of being understood and are aware of the facts and feelings central to the other’s self-conception (Reis & Collins, 2000). Secondly, it can be seen as an act of considerate protection – or protective buffering – of the other spouse, which involves hiding concerns, denying worries, and yielding to the partner to avoid disagreements as it is believed that talking and sharing will enhance distress and worry (Checton et al., 2012; Coyne & Smith, 1991; Skerrett, 2003).

**Couples Living with AF – an Implication for Systemic Intervention**

The thesis results suggest that there is a reciprocity and interdependence in the couple’s partner relationship, in which AF affects both members of the couple, but also that the spouses affect each other. Nonetheless, the partner or the couple as a unit is not systematically part of either nursing-care encounters or the target for interventional studies on AF. The few identified studies on nurse-led interventions in AF have been directed towards the patient and have focused on home-based education (Inglis et al., 2004) or nurse-led clinical care (Hendriks et al., 2012; Hendriks, Vrijhoef, Crijns, & Brunner-La Rocca, 2014). The interventions have had positive results in terms of fewer readmissions and shorter hospital stays (Hendriks et al., 2012; Inglis et al., 2004), better knowledge of AF (Hendriks et al., 2014), and more
comprehensive implementations of the guideline recommendations in the nurse-led intervention groups (Hendriks et al., 2012). Nonetheless, previous studies on partners to persons with AF have reported that feelings of alienation regarding knowledge and needing support and security concerning AF (Ekblad et al., 2014), interruptions of daily activities (Coleman, 2012), and the perceived impact of AF on quality of life are similar to those of patients (Bohnen et al., 2011). Combined with the results of the thesis, this indicates a need for considering or including the couple as a unit in interventional studies as well as in clinical work. The notion of including and targeting the couple – or the partner – in other chronic illnesses has previously demonstrated positive effects in terms of less depression and anxiety (Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Martire, Schulz, Helgeson, Small, & Saghafi, 2010), less caregiver burden (Martire et al., 2004), and a perception of enhanced marital functioning (Martire et al., 2010). On the other hand, a recent psycho-educational intervention that targeted dyads with heart failure did not find any significant improvement in health or emotional distress after either 12 months (Ågren, Evangelista, Hjelm & Strömberg, 2012) nor 24 months (Liljeroos, Ågren, Jaarsma, Årestedt & Strömberg (2015). Accordingly, Liljeroos et al (2015) argues that a possible explanation for the non-effectiveness of the intervention could be the lack of individualized focus. Nonetheless, Shields, Finley, Chawla, and Meadors (2012) concluded in their review that family interventions have the potential to reduce patient and caregiver distress, improve patient functioning through greater adherence to medical regimens, and strengthen family and couple relationships.

In light of this, clinical work and interventional studies using an FSN approach that conceptually takes interdependence into account could be a possible application for couples living with AF. A recent review on 17 interventions with an FSN framework (Östlund & Persson, 2014) found that the interventions improved the family members’ understanding and increased their confidence and capability to live with illness. Furthermore, families gained new and multiple
perspectives and an enhanced adjustment. FSN interventions on couples within a cardiovascular context have previously described positive outcomes on behalf of both couples and nurses. Duhamel, Dupuis, Reidy & Nadon (2007) found that couples experienced a relief of suffering and increased knowledge of each other’s feelings which prompted adjustment. Voltelen, Konradsen, & Østergaard (2016) found that nurses, working with persons with heart failure and their partners, experienced FSN to increase family bonding and enhancing family relationships.

An application of FSN is that of Family Health Promoting Conversations (FamHC) developed in Sweden (Benzein, Hagberg, & Saveman, 2008), which is considerably built upon the Calgary Family Intervention Model (CFIM) developed in Canada by Wright and Leahy (2013). Applications of FSN in the nursing of couples is operationalized within a number of structured conversation sessions between the patient/partner and a nurse (Benzein et al., 2008; Wright & Leahey, 2013). The operationalization of a systemic framework in FSN and FamHC is done by the nurse viewing the couple as a reciprocal interdependent system in which reality is co-created in human meetings and in interaction with the surroundings. Moreover, the nurse applies a non-hierarchical approach in which expertise for problem solving is not restricted to the nurse (Benzein et al., 2008; Wright, Watson, & Bell, 1996). The members of the couple are invited to share each other's perspective, which allows for the individual members of the couple to share their views and experiences in the situation but also get to listen to the other partner’s perspective (Wright & Leahey, 2013). The nurse then agrees, together with the couple, upon what aspect or situation is essential and most vital to talk about. Thus, different beliefs, both constraining and facilitating, are mapped within the couple. In order to achieve this, the nurse utilizes different intervening questions that facilitate reflection (Wright & Leahey, 2013; Wright, Watson & Bell, 1996). The orientation of the questions may be either difference (e.g., Who in the couple is most worried?), behavioral-effect (e.g., What do you do/feel when your spouse is sad?), or hypothetical/future (e.g.,
What will happen if the illness exacerbates?) (Wright & Leahey, 2013). Within the dialogue, questions help to achieve structural coupling between participants in the conversation that enhance the possibility to create a context for change (Wright, Watson, & Bell, 1996). Thus, the approach offered to couples aims to create a context for change; invite the telling of the illness narrative; and facilitate new beliefs, ideas, meanings, and possibilities in relation to the couple’s present concerns (Bell, 2015; Wright & Bell, 2009; Wright & Leahey, 2013; Östlund & Persson, 2014). Several recent FSN intervention studies using FamHC have shown that family members experienced support for problems that they had not been able to solve themselves as well as new understandings of their illness experience and relationships (Benzein et al., 2008; Benzein, Olin, & Persson, 2015; Östlund, Bäckström, Saveman, Lindh, & Sundin, 2016).

A fundamental aspect within FamHC is that the couple themselves – not the nurse – determine what the problem is or what they need/should address. Nonetheless, it is fair to assume that the clinical topics suggested by McCabe (2011) for working with persons with AF are also applicable to couples living with AF. The suggested topics to be addressed are (i) causes of AF, (ii) consequences of AF, (iii) course of AF, (iv) treatment, (v) action planning, and (vi) psychosocial response to AF.
Methodological Considerations

Considerations on the Aspect of Studying Couples

There are some notions regarding the aspect of studying couples together that need to be scrutinized. First, interviewing couples together, rather than patients and partners separately, may encourage participants to give answers that are perceived to be acceptable to the other spouse (Taylor & de Vocht, 2011). This means that patients or partners may have refrained from narrating what they actually experience or think about. However, as the thesis adopted a systemic perspective that views the couple as a reciprocal system, it was deemed appropriate and necessary to interview the couples together in order to grasp each couple’s mutual story and concerns. Thus, joint interviews may achieve results that are not achievable when conducting individual interviews; the joint interview provides the couple’s world of shared experiences and meanings (Taylor & de Vocht, 2011). Secondly, concerning the self-report questionnaires, participating couples were asked to fill them out independently and not to discuss their answers with each other. However, as the data were part of a larger multicenter study, and the participants received the questionnaires upon discharge to fill out at home, it cannot be ruled out that some couples filled out the questionnaires together. This could mean that some participants gave answers that are perceived to be acceptable to the other spouse.

Considerations on the Study Sample

The inclusion of couples in the thesis relied entirely on others rather than the author. From this, it is possible that couples with low marital satisfaction (perceived from the patient’s perspective) were not included, which suggests a bias toward couples with high marital satisfaction.

Combined, the three studies utilized convenient sampling (Polit & Beck, 2004), which poses a limit to the overall sample. Concerning GT, in which theoretical sampling directs what data to collect next, the
researcher would ideally situate the data collection to include couples based on what the data indicate (e.g., based on living arrangements or time as partners). As this was not possible, the process of theoretical sampling was limited to altering the interview questions based on what the concurrent data analysis indicated. In terms of study III, the process of data collection was performed over the course of four years. Embedded in this is that there are no data available on the total number of eligible participants, nor is there any data available on refusal to participate.

The total study sample for this thesis had a distribution of 60–40 in favor of the patient being male. This may indicate that women are underrepresented in the present thesis. However, the prevalence of becoming afflicted with AF is higher in men compared to women (Björck et al., 2013; Go et al., 2001; Kirchhof et al., 2016), and, similarly, in a large registry study on patients with AF, the surveyed sample of 7243 patients consisted of 40% women (Kirchhof et al., 2014). Thus, the present study sample may be regarded as reasonable in terms of distribution of male and female patients. Another aspect that might be considered is the average age of the patients. Within the registry study by Kirchhof et al. (2014), the mean age of patients was 71.5 years, whereas the present thesis had 63.6 (study II), 66.0 (study III), and 62.0 (study IV). Combined, this indicates that the thesis has a lower average age, which has adverse implications in terms of the sample being regarded as reasonable. The time as partners was, on average, 38.3 years (study II), 37.5 years (study III), and 41.9 years (study IV). This indicates that the couples have shared a great number of years together in which they have shared many experiences and have developed a mutual story. On the other hand, it points in the direction of a possible bias in the sample in favor of couples with high marital satisfaction (assuming that staying together as a couple is a measure for satisfaction).
Considerations on the Systematic Review (I)

A systematic review contains elements that are both qualitative and quantitative. Aspects that are quantitative may be found in the data collection process where the Boolean operators (AND, OR, NOT) are based on mathematical logic that defines and specifies relations among search terms. Qualitative aspects can be found in the process of analysis as it concerns the notion of extracting and grouping of text, which implies interpretation of the text on behalf of the researcher. From this, it can be argued that a systematic review contains both subjective and objective notions. According to Sandelowski (2008), the outcomes from a systematic review are highly subjective as they reflect the perspectives and preferences as well as the posed research questions of the authors. However, the systematic procedure itself is objective in the sense that the steps are communicable and, therefore, repeatable. A review becomes systematic if it adheres to a protocol that specifies the research questions; the type of research that will be reviewed; the process that will be used in the searching, selecting, and retrieving of the articles; the methods that will be used for quality assessment; and analysis of the findings (Sandelowski, 2008). As the current review adhered to the above protocol, it may be regarded as being systematic. However, following the reflections of Sandelowski and Barroso (2007), the search results presented in this review should be viewed in the context of guidance of the process, not a definite search result for each combination. Thus, as indexing problems and inconsistent search terminology may yield only 50% of eligible studies (Whittemore & Knafl, 2005), reference tables were screened. Quality assessment of potential articles was performed with the purpose of further validating the result. While this is argued to leave out research from reviews (Klainin & Arthur, 2009), quality assessment aims at preventing poor-quality research from distorting the final result (Evans, 2007). When analyzing the findings in a systematic review, different analysis designs are available, such as meta-analysis or meta-synthesis. Employing a meta-analysis requires a great deal from the individual studies – for instance, the sample populations and instruments used should be of
equivalent character. Moreover, qualitative studies are left out since they cannot be incorporated within the meta-analysis. A meta-synthesis, on the other hand, is more approachable when systematically reviewing qualitative studies. As this review incorporated both qualitative and quantitative studies, neither was deemed relevant or applicable. Instead, an approach inspired by Whittemore and Knafl (2005) combining qualitative and quantitative studies was utilized.

Lastly, there are some clarifications regarding study I that need to be addressed. The included study by Dinesen, Nøhr, Andersen, Sejersen, and Toft (2008) is reported in study I to be a mixed-method study when, in fact, it was a phenomenological-hermeneutic study. Moreover, study I reported that a total of five studies utilized a phenomenological approach. For clarification purposes, there were two studies that used phenomenology while three studies used phenomenological-hermeneutics. Additionally, studies with a quantitative method utilized a cross-sectional and correlational design (n = 3) while one study utilized mixed method.

**Considerations on the Qualitative Studies (II and IV)**

**Classical Grounded Theory (II)**

GT does not aim to describe; rather, it aims to explain. As the systematic review did not identify any studies on couples living with AF, a classical GT was deemed appropriate as the research question arises from the data as well as its aim to explain what happens in the couple. According to Glaser (1998), a GT is not to be considered as findings; rather it is an integrated set of conceptual hypotheses. Therefore, a GT can never be considered right or wrong; it can only be evaluated based on its fit, relevance, workability, and modifiability. The concept of fit means that the categories must fit the data; that is, data should not be forced or selected to fit preconceived or preexistent categories. Through constant comparison, codes and categories are constantly compared with newly generated codes and concepts throughout the course of the study. Relevance means that the emerged categories are related to and
deal with the participants’ real concern – that is, the categories must be relevant to the main concern. Workability implies that the theory explains how the main concern is resolved. Modifiability involves comparing new data with the existing data, thus enabling modification of the theory. The literature review in this study contributed to the theory’s relevance, workability, and modifiability. In addition, presenting the categories to patients and healthcare professionals at an open seminar on cardiac arrhythmia gave support to the theory’s fit, relevance, and workability. Because GT is abstract with regard to time, place, and people, the theory of Managing Uncertainty may contribute to understanding couples living with other chronic diseases with unpredictable symptomology and reoccurrence. However, further research is required to make the theory applicable to other chronic diseases.

Hermeneutics (IV)

As Gadamerian hermeneutics is a philosophy and not a method per se, it lacks a methodological framework for data collection and analysis. Nevertheless, it is a well-adopted perspective within qualitative research for gaining understanding through interpretation. The trustworthiness of a Gadamerian hermeneutic study may adopt the criteria for quality of qualitative research as described by Lincoln and Guba (1985), i.e., credibility, confirmability, dependability, and transferability (Fleming et al., 2003). Through a thorough description of the applied research process, procedure for data collection, data analysis process, the credibility of study is strengthened. A detailed description of the participants enhances the transferability of the findings beyond the context of couples living with AF. Moreover, the findings share similarities and congruence with previous studies concerning illness beliefs, which also favor transferability. Throughout the interpretative analysis process, the researcher’s preunderstanding was, following Gadamer (1994), scrutinized to avoid the preconceptions that were projected being irrelevant and arbitrary to the subject matter. As the researcher has had experiences in clinical work with cardiac patients as well as family-centered research, the projected preconceptions were
deemed relevant, which strengthened the confirmability in the present study. To strengthen dependability in the present study, all interviews were conducted by the same researcher, and the same main questions guided the interviews.

**Considerations on the Quantitative Study (III)**

*Internal validity* refers to the extent to which it is possible to make an inference that the independent variable is truly influencing the dependent variable and that the relationship between the two is not the spurious effect of an extraneous variable (Polit & Beck, 2004). A great threat to internal validity is selection bias, which is related to inclusion of participants. Regarding the study sample, there is no information on the total number of eligible participants nor any data on refusal to participate. Additionally, as inclusion in the study was not based on random allocation from a general AF population, it is possible that there are inequalities in the present sample, which would limit the internal validity. Moreover, the aspect of *construct validity* refers to what an instrument actually measures (Polit & Beck, 2004). It may be argued that there are conceptual overlaps in the constructs of the HADS and MCS in the SF-36. However, the HADS measures two different concepts – symptoms of anxiety and symptoms of depression – while the MCS also includes social functioning (e.g., interference with normal social activities with family or friends) and emotional role functioning (e.g., less time spent on work or other activities). Thus, the MCS in the SF-36 includes other aspects not covered in the two different concepts in the HADS. Moreover, as the study aimed to examine whether emotional distress was associated with perceived health, it also raises the obvious question: What if it is the other way around, i.e., perceived health is associated with anxiety and symptoms of depression? As several studies have linked emotional distress as a predictor for impaired health-related quality of life in patients living with AF, the hypothesized association may be considered mitigating for the validity in the study. Nonetheless, as the study used a cross-sectional design, it is difficult to state any inferences of causality (Altman, 1991), i.e., that
emotional distress leads to – or predicts – worsened health and not the opposite. *External validity* concerns the applicability or generalizability of the results beyond the study group toward other populations, settings, and circumstances (Polit & Beck, 2004). Threats to external validity in the study can be attributed to lack of randomization, lack of available data on the number of eligible participants, and lack of available data on refusal to participate. Combined, this brings difficulties in regarding the sample as representative to the population, thus limiting the external validity in the study. *Statistical conclusion validity* refers to the degree to which conclusions about relationships and differences from the statistical analysis are legitimate (Polit & Beck, 2004). The absence of an initial power analysis to determine the appropriate number of participants limits the statistical conclusion validity in the study. Power refers to the extent to which an investigation can detect a difference when a difference actually exists (Altman, 1991; Kazdin, 2003), i.e., minimize the risk of a type II error. In some other identified APIM studies conducted in a cardiovascular context, the numbers of participating couples were $n = 58$ (Chung, Moser, Lennie, & Rayens, 2009), $n = 138$ (Vellone et al., 2014), and $n = 84$ (Thomson, Molloy, & Chung, 2012). Thus, the sample size of 91 couples for study III seems to conform reasonably with previous studies. Nevertheless, the absence of an initial power analysis, the lack of data on the total number of eligible participants, and lack of data on refusal to participate brings difficulties in regarding the sample as a reasonable representation of the population. As such, the results from study III should be interpreted with caution.
Conclusions

This thesis – and the individual studies within – is a contribution to the existing literature and research on couples living with chronic illness and, in particular, couples living with AF. As an overall conclusion, the thesis results suggest that there is a reciprocity and interdependence in a couple’s partner relationship, in which AF affects both members of the couple, but also that the spouses affect each other. Thus, as an interdependent feedback system, the couple members affected and influenced each other on aspects such as making sense of AF, responding to AF, and mutually incorporating and dealing with AF in their daily lives. Moreover, the previously unknown aspects of how the partner relationship is affected in couples living with AF can be seen as indications and suggestions regarding clinical work with persons with AF and their partners. As the results agree with previous studies on close relationships and chronic illness, this thesis further supports the fact that cardiac disease and AF are chronic illnesses with a profound effect on afflicted couples. More specifically, the thesis may conclude the following:

- Cardiac disease consumes multiple aspects of a couple’s relationship and daily life; physical issues, such as sexual concerns; psychological issues, such as withholding feelings and not communicating; social issues, such as changes in domestic roles and responsibilities.
- AF affects the partner relationship by bringing uncertainty into the couple’s daily life; it poses a challenge by inflicting something that is unknown and excursive to them. The uncertainty is related to not knowing what AF is or what underlying factors contribute to the development of AF.
- Time since diagnosis and elapsed time being symptom-free seem to work as mitigating factors for tacit understanding in afflicted couples.
• Concealment of feelings or not talking about AF should not necessarily be interpreted as detrimental in terms of low relationship quality or an act of repressing the illness. Rather, couples that have shared many years together have developed a mutual understanding of each other’s feelings and concerns, which are communicated and appraised through other sources such as how one sighs or glances.

• The results indicate that it is important to recognize emotional distress in both persons with AF and their partners as emotional distress is associated with vitality in terms of energy and tiredness in couples with AF.

• AF elucidated beliefs that challenged the couple’s existence and posed a threat to life but also engendered beliefs that change is natural and that, when changes occur, it is natural to adapt and adjust to maintain or gain control.

• Even though afflicted couples are confronted with changes and challenges, they conform and adjust their relationship and daily lives to the new situation. Additionally, even though AF imposes limitations and restrictions on daily life, these were not regarded with profound pessimism by couples; rather, just as change is natural, so is adaptation.

Implications for Practice and Research

The introduction and rationale sections of this thesis argued that, if the formalized and professional care of persons with AF and their partners are to be thoroughly substantiated, research is needed regarding how their daily lives and relationships are affected – both to generate knowledge and to be able to create appropriate interventions. In the light of this, the thesis results suggest that clinicians working with persons with AF and their partners should employ a systemic view with consideration of couples reciprocity and interdependence but also have knowledge regarding AF in terms of pathophysiology, the nature of AF (its cause, consequences, and trajectory), and treatments. The findings
also suggest that clinical work with couples living with AF should take its starting point from the couple’s mutual story – how they perceive AF and what challenges they experience. A possible approach to achieve this is a clinical utilization of an FSN based framework, such as the FamHC, which allows for the uncovering of couples’ illness beliefs and main concerns. These aspects are important as they guide couples’ decisions and actions that ultimately affect how the couple manage and deal with AF in their relationship and daily lives. Even if a formalized FSN framework is not utilized, partners should not be neglected but, rather, be considered a resource and be a part of clinical caring activities. This could be achieved by inviting partners to take part in follow-up visits or other clinical caring activities. Clinicians operating at in-hospital settings should invite partners to participate throughout the hospital stay regarding rounds, treatment decisions and discharge calls, whilst clinicians in primary care settings should invite partners to participate in follow-up meetings.

However, additional studies are needed to thoroughly substantiate the clinical care directed towards persons with AF and their partners. Interventional studies using an FSN-based framework, such as FamHC, could be regarded as a viable opportunity for couples living with AF. Follow-up and evaluation of such an intervention should be done using both qualitative methods and quantitative methods. Future APIM studies should include control variables such as time as partners, type of AF, time since diagnosis AF, or gender when estimating the associations. Future studies should also broaden the perspective to include other family members, such as children or other relatives, in order to explore how AF is perceived and dealt with within a larger family system.
Svensk sammanfattning

Introduktion
Människor lever i system, eller sociala konstruktioner och miljöer, där våra handlingar och beteende påverkar andra människor direkt och/eller indirekt – likaså, andra människor inverkar och påverkar oss genom sina handlingar och beteenden. Sjukdom och ohälsa kan ses som en social företeelse, med vilket avses att när en person drabbas av sjukdom så påverkar inte detta bara den personen utan även personer i dennes närhet. Utifrån ett systemiskt perspektiv skiftas fokus ifrån individen till gruppen, samt ifrån symtom och diagnos till relationer och samspel med miljön. Personer som lever tillsammans i en parrelation kan ses som ett ömsesidigt och beroende system, och utifrån detta så fokuserar denna avhandling på paret som analysenhet.

Tidigare forskning inom kronisk sjukdom har påvisat flera konsekvenser och implikationer på parrelationen, men att det finns en brist på forskning inom det kontextuella perspektivet att leva med förmaksflimmer (FF). Personer med FF har sämre livskvalitet jämfört med en generellt frisk population samt personer med andra hjärtsjukdomar. Likaså upplever personer med FF lägre personlig kontroll över sin sjukdom jämfört med personer med andra hjärtkärlsjukdomar. Partners till personer med FF har i studier beskrivit känslor av oro, hinder i dagliga aktiviteter och lika nivåer av livskvalitet som personer med FF.

Om den professionella och formaliserade vården av personer med FF och deras partner ska vara väl underbyggd, behövs forskning om hur paret upplever sjukdomen i deras relation och det dagliga livet samt hur de hanterar sin situation – både för att generera kunskap men även för att möjliggöra upbyggnad av kvalificerade insatser och interventioner. Avhandlingens övergripande syfte var därför att beskriva och utforska hur parrelationen påverkas hos par där den ena partnern har hjärtsjukdom – och i synnerhet – förmaksflimmer.
**Design och metod**

Utifrån de specifika delsyftena användes olika forskningsdesigner; beskrivande (I), explorativ (II, IV) och en tvärsnittsdesign (III). Applicerade metoder innefattade en systematisk litteraturstudie (I), kvalitativa metoder (II, IV) och kvantitativa metoder (III).

Deltagare i studierna var par där den ena partnern har diagnosticerats med förmaksflimmer. Delstudie I syftade till att identifiera och beskriva det aktuella forskningsläget, vilket gjordes genom en systematisk litteraturgenomgång där 20 artiklar analyserades genom en integrativ analys. Delstudie II syftade till att utforska pars huvudangelägenhet och hur de kontinuerligt hanterar denna; 12 par intervjuades vilket analyserades genom classical grounded theory. Delstudie III syftade till att studera sambandet mellan känslomässig stress och upplevd hälsa mellan patienter och partners; 91 par analyserades genom Actor-Partner Interdependence Model. Delstudie IV syftade till att utforska sjukdomsföreställningar hos par; 9 par intervjuades vilket analyserades utifrån hermeneutik såsom beskriver av Gadamer.

**Resultat**

studierna i den systematiska litteraturstudien studerade par i kontexten FF, vilket initierade ett fortsatt fokus på parrelationen där den ena partnern har FF.

Par som lever med FF upplever en gemensam osäkerhet kopplat till två aspekter, (i) att inte veta vad FF är och (ii) att inte veta om, när och varför en FF-episod inträffar (II). Paren hanterar osäkerheten genom två övergripande strategier: explicit delande (gemensamt samarbete och hitta likheter) och implicit delande (distansering och tyst samförstånd). Ett explicit delande innefattar, dels ett gemensamt samarbete (t.ex. planerar resa tillsamman); pratar om symtom/söka sjukvård etc), dels att hitta likheter (t.ex. jämför med andra som lever med hjärtsjukdom). Ett implicit delande innefattar, dels distansering (man vill inte oroa varandra; håller inne på känslor/tankar), dels ett tyst samförstånd (känner varandra – behöver inte prata om allt; man vet hur/vad den andra partnern känner eller tänker på). Vidare spelar tiden en avgörande roll i hur paren hanterar och upplever osäkerheten; då längre tid har förlutit mellan FF-episoder tenderar paren att prata mindre om FF samt upplever mindre oro och osäkerhet – alltså, ett skift mot implicit delande. Om episoder av FF återkommer mer frekvent tenderar par att skifta över till explicit delande.

Tidigare studier inom FF har påvisat att det finns samband i vilket ångest/depression är associerad med självskattad hälsa. Genom modellen The Actor-Partner Interdependence Model (APIM) är det möjligt att studera interaktionen inom paret – alltså, hur en persons ångest/depression är associerad med, dels den egna självskattade hälsan (aktörseffekt), dels hur personens ångest/depression är associerad med den självskattade hälsan hos dennes partner (partnereffekt) (III). Resultatet fann att patienter och partners visade signifikanta skillnader avseende självskattad fysisk och psykisk hälsa, där patienter skattade sig lägre än partners. Flera aktöreffekter identifierades, vilket indikerar att känslosammast stress (ångest/depression) är associerad med självskattad hälsa. Partnereffekter observerades för vitalitet, vilket indikerar att symtom på depression är associerad med vitalitet i den andra partnern.
Föreställningar är konstruktioner och tro som vi har kring olika fenomen, situationer och företeelser. Det är utifrån våra föreställningar som vårt beteende styrs och våra liv konstrueras – individuellt och tillsammans med andra. Par som lever med FF har föreställningar (IV) om hjärtat som en symbol/framställning av livet och när symbolen för livet blir drabbat av sjukdom ses det som ett hot mot livet – det är inte som att bryta armen, det är mer allvarligt. När livet hotas vill man kunna förklara och förstå sjukdomen (FF), vilket gör att man söker efter bakomliggande orsaker/förklaringar till FF. Likaså, att drabbas av sjukdom i sig ses inte som något konstigt eller avvikande – livet är fullt av händelser som innebär förändring – förändring ses alltså som något normalt. Även om förändringen ses som normal så ses FF som en störning i livet; det stör parets självbild som hälsosamma personer. Å andra sidan ska dessa förändringar inte förstöra vårt liv. Att äta saker och ting har en negativ effekt och leder inte till att FF försvinner; vi kan inte sluta leva som en konsekvens av FF. Eftersom paren ser förändring som något naturligt ses även anpassning som något fundamentalt i livet – vi anpassar oss alltid. Förändring är nära kopplat till att ha kontroll.

FF hotar den kontrollzon som paret har – och om FF kan kontrolleras så kan också zonen där man känner sig bekväm kontrolleras; paret bestämmer. Å andra sidan så kan andra bestämma kontrollzonen – genom medicinering och behandling. Även genom att träffa samma sjukvårdspersonal eller att ha tillgång till vård som paren känner till.

Slutsatser
Avhandlingen – och de enskilda studierna – är ett bidrag till den existerande litteraturen och forskningen avseende par som lever med kronisk sjukdom och – framför allt – avseende par som lever med FF. Övergripande tyder avhandlingens resultat på att det finns en ömsesidighet där FF påverkar både personen med FF och dennes partner, men också att de påverkar varandra. Paret kan ses som ett ömsesidigt och beroende återkopplingssystem avseende att gemensamt försöka förstå FF, att gemensamt bemöta FF, samt ömsesidigt integrera och hantera FF i sitt dagliga liv. Dessa aspekter om hur parrelation
påverkas hos par med FF, kan utgöra grund och förslag till utformning av det kliniska arbetet med personer med FF och deras partner. Vårdpersonal som arbetar med personer med FF och deras partner bör utgå ifrån ett systemiskt synsätt med hänsyn till parets ömsesidighet och ömsesidiga beroende, men också ha kunskap om FF avseende patofysiologi, konsekvenser och behandlingar. Ett möjligt sätt att uppnå detta i klinisk verksamhet kan vara en tillämpning av ett FSN-baserat arbetssätt genom hälsostödjande familjesamtal (FamHC). Hälsostödjande familjesamtal möjliggör kartläggning och synliggörande av parets föreställningar och huvudangelägenheter, vilket är viktiga aspekter då de vägleder paret avseende beslut och hantering av FF i deras relation och vardag. Även om en formaliserad del av hälsostödjande samtal inte införs i klinisk verksamhet, bör dock partners inte negligeras utan snarare ses som en resurs och bjudas in till att delta i vårdmötet. Vårdpersonal som arbetar i slutenvård bör uppmuntra och bjuda in partnern till att delta under sjukhusvistelsen avseende, t.ex. rond och utskrivningssamtal. Likaså bör vårdpersonal i primärvården uppmuntra partner att delta i uppföljningsbesök. Utifrån ett systemiskt synsätt bör framtida interventionsstudier omfatta paret som analysenhet liksom också utgöra målet för interventionen.


