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Patients' experiences of atrial fibrillation and an evaluation of a nurse-led person-centred clinic

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Table of Contents

Abstract	iii
Sammanfattning på svenska	v
Preface.....	vii
Abbreviations	viii
Original papers.....	ix
Introduction.....	1
Background	3
Living with atrial fibrillation	3
Atrial fibrillation.....	4
Management of atrial fibrillation	5
Person-centred care.....	8
Patient-reported outcomes.....	9
Health-Related Quality of Life	10
Illness perceptions.....	11
Rationale	14
Aims.....	15
Materials and Methods	16
Settings	16
Participants.....	16
Data collection and procedure.....	19
Analysis.....	26
Ethical considerations	28
Results.....	30
Discussion	40
Conclusions	53
Clinical implications and future research	53
Acknowledgements – Tack	55
References.....	57

Abstract

Background: Living with and managing atrial fibrillation (AF) can be complex. Some people have no symptoms, while others have a significant symptom burden. Health-related quality of life (HRQoL) is often low and partly associated with symptom burden. However, the impact of the condition on daily life differs between those affected and is not fully understood. Therefore, more knowledge is needed about patients' experiences of AF and factors influencing HRQoL. Research indicates that the care of patients with AF needs to change and be more based on personal preferences and values.

Aim: The overall aim of this thesis was to explore patients' experiences of AF and to evaluate the effects of a nurse-led, person-centred clinic.

Methods: The thesis contains four studies. Study I was based on interviews with 15 patients about their experiences of living with symptomatic AF. Studies II and III were based on data from questionnaires completed before and 6 months after scheduled electrical cardioversion. Study II was a cross-sectional study with 52 women and 115 men describing illness perceptions and HRQoL and exploring their relationship. Study III was a longitudinal study comparing 53 newly diagnosed (<6 months) and 76 previously diagnosed patients with AF (≥ 6 months) regarding HRQoL, illness perceptions, symptoms, symptom burden, anxiety and depression. Study IV was a randomised controlled trial evaluating the effects of a nurse-led, person-centred clinic on patient-reported outcomes measures in patients with AF. Patients were randomly assigned to a nurse-led intervention group (n=50) or a control group with a physician visit (n=53) and completed questionnaires on the same subjects as in Study III at baseline before the visit to the clinic and 6 months after. Study I were analysed with qualitative content analysis. The other studies are quantitative and were analysed with descriptive statistics (Studies II–IV), comparative statistics (Studies II–IV), and correlation analysis and multiple linear regression analysis (Study II).

Results: In Study I, three themes (striving for illness control, becoming a receiver or an active partner in care, and dealing with a changed self-image) were reflected in the main theme, balancing life. The participants described their struggles in understanding AF, preventing recurrence and managing anxiety. Some were not involved in decision-making, lacked continuity of care, felt that most information focused on medical issues and requested more support and self-care advice. Study II showed

that HRQoL was related to and negatively affected by attributing more symptoms, severe consequences, and negative emotions (e.g., anxiety, anger) to AF and perceiving AF as recurrent. Women reported worse HRQoL and lower personal control than men. Study III showed that newly diagnosed (vs. previously diagnosed) patients at baseline reported AF as a more temporary condition to a greater extent and had stronger belief that the illness was controllable. After 6 months, newly diagnosed patients reported better HRQoL, higher personal control, and lower symptom burden than previously diagnosed patients. Over time, HRQoL improved and AF symptom burden and symptoms of anxiety decreased in newly diagnosed patients, who viewed the illness as chronic to a greater extent than at baseline. Study IV showed that, in the nurse-led intervention group, the patients' negative emotions towards AF decreased more than in the control group. In addition, their concerns regarding AF decreased and their personal control increased. In both groups, HRQoL and patients' understanding of AF improved.

Conclusions: This thesis demonstrates that for many, AF meant a change in life in which they had to manage anxiety and symptoms and oscillate between being strong and weak and a changed self-image. Men (vs. women) and newly diagnosed (vs. previously diagnosed) patients reported more positive outcomes, such as better HRQoL and greater belief in their ability to control AF. Worse HRQoL was associated with negative illness perceptions, such as more perceived recurrences, symptoms, severe consequences, and negative emotions. The findings in Study IV suggest that the support from a nurse-led person-centred clinic may reduce patients' negative emotions and concerns attributed to AF and improve their personal control.

Key words: anxiety, atrial fibrillation, experiences, health-related quality of life, illness perception, nursing, nurse-led clinic, patient-reported outcomes, person-centred care, randomised controlled trial, symptoms, symptom burden

Sammanfattning på svenska

Bakgrund: Att leva med och hantera förmaksflimmer (FF) kan vara komplext. Vissa har inga symptom medan andra har en betydande symptombörda. Den hälsorelaterade livskvaliteten är ofta låg och delvis förknippad med symtombördan. Tillståndets inverkan på det dagliga livet skiljer sig åt mellan de som drabbas och är inte helt klarlagd. Därför behövs mer kunskap om patienters upplevelser av att leva med FF och de faktorer som påverkar hälsorelaterad livskvalitet. Tidigare forskning tyder på att vården för patienter med FF behöver förändras och i större utsträckning utgå från deras personliga preferenser och värderingar.

Syfte: Det övergripande syftet med avhandlingen var att utforska upplevelser av FF samt utvärdera effekterna av en sjuksköterskeledd, personcentrerad mottagning.

Metod: Avhandlingen består av fyra delstudier. Studie I var en intervjustudie med 15 deltagare om deras upplevelse av att leva med symptomgivande FF. Studie II och III baserades på enkätdata, som fylldes i av patienter före deras planerade elkonvertering och efter sex månader. Studie II var en tvärsnittsstudie, med 52 kvinnor och 115 män, som beskrev sjukdomsuppfattningar och hälsorelaterad livskvalitet och undersökte sambandet mellan dessa. I Studie III, som var longitudinell ingick 53 nyligt diagnosticerade patienter (<6 månader) och 76 patienter som haft diagnosen längre (≥6 månader). De jämfördes gällande hälsorelaterad livskvalitet, sjukdomsuppfattningar, symptom, symtombörda, ångest och depression. Studie IV var en randomiserad kontrollerad studie som utvärderade effekterna av en sjuksköterskeledd, personcentrerad mottagning på patientrapporterade utfallsmått hos patienter med FF. Deltagarna lottades slumpmässigt till sjuksköterskeledd interventionsgrupp (n=50) eller en kontrollgrupp (n=53), som träffade läkare. Deltagarna fyllde i enkäter inom samma ämnesområden som i studie III, vid baslinjen före besöket på mottagningen och sex månader efter.

Resultat: Analysen av studie I resulterade i huvudtemat Att balansera livet, vilket återspeglade de tre temana: strävan mot sjukdomskontroll, att vara mottagare av eller aktiv partner i sin vård och att hantera en förändrad självbild. Deltagarna beskrev sin kamp för att lära sig förstå FF, förbygga återfall och hantera ångest. Vissa var inte involverade i beslutsfattande och saknade kontinuitet i sin vård. Informationen de fick upplevdes fokusera mestadels på medicinska frågor och deltagarna

efterfrågade mer stöd och egenvårdsråd. Studie II visade att hälsorelaterad livskvalitet var relaterat till och påverkades negativt av de symtom, konsekvenser och de negativa känslorna (t.ex. ångest, ilska) som patienterna tillskrev FF och även uppfattningen att FF var återkommande påverkade. Kvinnorna rapporterade sämre hälsorelaterad livskvalitet och lägre tro på sin förmåga att hantera sjukdomen än männen gjorde. Studie III visade att patienter som nyligen diagnosticerats rapporterade mer positiva utfall jämfört med de som haft FF längre. De uppfattade i större utsträckning sjukdomen som kontrollerbar. Vid sex månader rapporterade de nyligen diagnosticerade bättre hälsorelaterad livskvalitet, större tro på att kunna hantera sjukdomen och lägre symtombörda än de som haft diagnosen längre. Studie IV visade att i den sjuksköterskeledda interventionsgruppen minskade deltagarnas negativa känslor mot FF i större utsträckning jämfört med kontrollgruppen. Dessutom minskade deras oro och bekymmer angående FF, och deras tilltro till sin förmåga att kontrollera AF ökade. Båda grupper visade förbättringar i hälsorelaterad livskvalitet och förståelsen för tillståndet.

Slutsats: För många innebär FF en förändring i livet där personerna behöver hantera såväl ångest som symtom och pendla mellan att vara starka och svaga samt en förändrad självbild. Kvinnor jämfört med män och de med en äldre diagnos av FF jämfört med nyligt diagnostiserade patienter, rapporterade sämre hälsorelaterad livskvalitet och lägre tro på sin förmåga att kontrollera FF. Försämrad hälsorelaterad livskvalitet associerades med negativa sjukdomsuppfattningar, såsom exempelvis upplevelsen av fler återfall, symtom, svåra konsekvenser och negativa känslor. Fynden i studie IV tyder på att stödet från en sjuksköterskeledd personcentrerad mottagning kan minska patienters negativa känslor och den oro som tillskrivs FF och stärka deras tro på att kunna hantera sjukdomen.

Nyckelord: ångest, förmaksflimmer, upplevelser, erfarenheter, hälsorelaterad livskvalitet, sjukdomsuppfattning, omvårdnad, sjuksköterskeledd mottagning, patientrapporterade utfall, personcentrerad vård, randomiserad kontrollerad studie, symtom, symtombörda

Preface

Caring for patients with atrial fibrillation (AF) has been part of my work since 1986, when my career in cardiac care began – first as an assistant nurse and later as a registered nurse (RN). When I started working as a cardiac nurse in the outpatient clinic, I realised how problematic life could be for these patients. Many patients phoned the clinic because they did not know who to turn to with their questions. They were worried and did not know how to manage their symptoms or avoid recurrence; moreover, they did not know when it was time to seek care, which may explain why they sought care often. After years of discussion at the clinic, it was decided that a nurse-led AF clinic would be implemented. This decision and the later design of the outpatient clinic were partly based on interviews carried out with patients with AF, which would later become the basis of Study I in this thesis. As an RN working at the clinic, I had the opportunity to be involved in the planning of the nurse-led, person-centred AF clinic.

In the spring of 2020, during the COVID-19 pandemic, I started my professional journey as a PhD student. I had the opportunity to investigate what it is like to live with AF and to evaluate the newly implemented nurse-led clinic. This thesis contributes to an expanded understanding of the experiences of living with AF.

Abbreviations

AF	Atrial fibrillation
ASTA	The Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia
B-IPQ	The Brief-Illness Perception Questionnaire
CHA ₂ DS ₂ -VASc	Congestive heart failure, Hypertension, Age ≥ 75 years, Diabetes mellitus, Stroke, Vascular disease, Age 65 – 74 years, Sex category (female)
CSM	Common-Sense Model of self-regulation
ESC	The European Society of Cardiology
GPCC	The University of Gothenburg Centre for Person-Centred Care
HADS	The Hospital Anxiety and Depression Scale
HRQoL	Health-Related Quality of Life
IPQ-R	The Revised Illness Perception Questionnaire
PCC	Person-centred care
PRO	Patient-reported outcome
PROM	Patient-reported outcome measure
QoL	Quality of Life
RN	Registered Nurse
SD	Standard Deviation

Original papers

This thesis is based on the following studies, which are cited in the thesis by using their Roman numerals:

- I. Holmlund, L., Hellström Ängerud, K., Hörnsten, Å., Valham F., Olsson K. (2023). Experiences of living with symptomatic atrial fibrillation. *Nurs Open*. 10(3):1821-1829. doi:10.1002/nop2.1442
- II. Holmlund, L., Hörnsten, C., Valham, F., Olsson, K., Hörnsten, Å., Ängerud, K.H. (2024). Illness perceptions and health-related quality of life in women and men with atrial fibrillation. *J Cardiovasc Nurs*. 39(1):49-57 doi:10.1097/jcn.0000000000000995
- III. Holmlund, L., Hörnsten, C., Hörnsten, Å., Olsson, K., Valham, F., Ängerud, K.H. (2024). More positive patient-reported outcomes in patients newly diagnosed with atrial fibrillation – a comparative longitudinal study. *Eur J Cardiovasc Nurs*. Online ahead of print Jan 03, 2024. <https://doi.org/10.1093/eurjcn/zvad139>
- IV. Holmlund, L., Hörnsten, C., Valham, F., Olsson, K., Hörnsten, Å., Katsoularis, I., Salonen, L., Ängerud, K.H. (In manuscript). The effects of a nurse-led, person-centred clinic on patient-reported outcomes in patients with atrial fibrillation – a randomised controlled trial.

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Introduction

For most people, symptoms related to the heart are worrisome. Symptoms of atrial fibrillation (AF) are no exception. Moreover, in addition to creating anxiety, AF can affect physical ability, which in turn can lead to major limitations in life. However, patients affected by AF can exhibit great differences; some have no symptoms, while others have a significant symptom burden. Health-related quality of life (HRQoL) is often worse in people with AF than in people with other cardiovascular heart diseases. Symptoms and a prominent symptom burden contribute to worse HRQoL. However, worse HRQoL is not always solely explained by a high symptom burden; other factors may also contribute, such as age, gender, comorbidities and how well the person accepts having AF. Studies suggest that a person's perception of the illness can affect HRQoL, although few studies have been conducted in people with AF.

Many resources are spent on treating AF with medical and surgical treatments, often rendering patients symptom-free and improving their HRQoL. However, AF tends to recur for many, these treatments are unsuitable for some, not everyone will be symptom-free and treatment can be costly. In addition, recent research suggests that managing risk factors with lifestyle changes can reduce the symptoms and worsening of AF. Despite the growing number of patients with AF who actively seek care and are present throughout the care chain, there appears to be a noticeable lag in the provision of care, both globally and in Sweden. These patients express a need for support and for someone to turn to with questions, and patient associations emphasise the necessity for improvements in healthcare.

In this thesis, I use the terms 'persons with AF' and 'patients with AF'. The studies and sampling were performed in a hospital environment where persons with AF are labelled as 'patients' during their hospital visit. However, this wording is not intended to mean that these individuals are viewed as patients when they are managing the symptoms and illness at home in their natural environment on the other days of the year. There, they are instead persons diagnosed with AF, who may also be parents, children, siblings, friends, neighbours or workmates, striving to fulfil their social roles as usual despite the illness and its symptom burden, treatment and care.

Since people with AF make up a multifaceted group with major differences in symptoms, causes of AF and HRQoL, care that is more

person-centred is needed. Person-centred care (PCC) focuses on the person's preferences, resources, experienced needs and values in decisions about care and treatment. Furthermore, it has a broadened perspective of illness in which the patient's narratives and experiences are prominent. It focuses on the patient's participation in his or her own care, collaboration between the patient and healthcare professional, and the formulation of a health plan. In order to improve care, a nurse-led person-centred clinic for patients with AF was implemented at a cardiovascular outpatient clinic at a university hospital in Sweden.

Background

Living with atrial fibrillation

Living with AF is described differently by the different people affected by it. Some experience few or no symptoms of AF. For many others, AF causes major problems in their daily activities, rendering them unable to work or plan trips; for some, their sex life is also affected.^{1,2} Patients describe experiencing unpredictable^{1,3} and frightening symptoms¹ that cause anxiety, delayed diagnosis, disappointment due to repeated treatment failures, and feelings of a lack of support.³ Treatment with oral anticoagulant therapy can also cause anxiety and affect people's lives and lifestyles.² The impact of AF is not only limited to the person experiencing it; also the well-being of relatives can be affected due to their worries,⁴ and the fear of another episode of AF.⁵

Symptoms that arise because of AF can be experienced in different ways.⁶ Common symptoms include dyspnoea, fatigue, and palpitations. Other symptoms include dizziness, tiredness and chest pain.⁷ However, 50%–87% of people with AF are initially asymptomatic,⁸ which may carry a less favourable prognosis, as a lack of symptoms is associated with an increased risk of ischemic stroke and death.⁹ The objective measure of *AF burden* can be defined as ‘the amount of time spent in AF divided by the total amount of time a patient is monitored’,^{10 (p.14)} regardless of whether the AF is symptomatic or asymptomatic. In general, the *symptom burden* can be defined as the ‘subjective, quantifiable prevalence, frequency, and severity of symptoms that place a physiologic burden on patients and may produce multiple negative physical, psychological, and emotional patient responses’.^{11 (p.677)} Women with AF tend to be more symptomatic¹² and experience a more noticeable symptom burden than men.¹³ Symptom burden in patients with AF can be measured via self-reported questionnaires. The European Heart Rhythm Association (EHRA) symptom scale¹⁴ is a measure healthcare professionals use to quantify AF-related symptoms in order to evaluate how symptoms affect the patient’s daily activity and to guide AF treatment decisions.⁸ However, there may be discrepancies between patient-reported symptoms and physician-assessed symptoms.¹⁵

Patients with AF report a high treatment burden, which may be higher than that for other chronic illnesses, especially in women and younger patients.¹⁶ The term *treatment burden* refers to the frequency of

physician appointments, diet modification, requirements for physical activities and all factors that remind the individual of health problems—that is, treatment-related activities¹⁷ – and has been shown to affect HRQoL.¹⁶ Problems that can arise with frequent visits to different healthcare providers have been clearly described in a study by Hoegh et al., which showed how difficult it was to be a patient and to remember and understand the advice and information from different healthcare providers.¹⁸ Few other studies have described the well-being over time of people with AF. In a study by McCabe et al., it was found that the participants could tolerate living with AF if they had to, but they did not seem willing to accept it and actively searched for a remedy.³ Research indicates that living with AF can be complex and varies greatly; however, the literature concerning patients' experiences of AF is still sparse, and further studies are needed.

Atrial fibrillation

AF is defined as 'a supraventricular tachyarrhythmia with uncoordinated atrial electrical activation and consequently ineffective atrial contraction'.⁸ (p.385) A diagnosis of AF requires documentation of the AF rhythm with a single-lead electrocardiogram (ECG) for ≥ 30 s or a standard 12-lead EKG.^{8,19} Based on its presentation, duration and termination of episodes, AF can be categorised into five types: first-time diagnosed, paroxysmal, persistent, long-standing persistent and permanent.⁸

Many people live with AF, and it is considered the most common arrhythmia among the adult population, with an approximately 2%–4% prevalence.⁸ Despite its high prevalence, AF is underdiagnosed, in part because it can be asymptomatic, especially at onset.⁶ Worldwide,^{20,21} as well as in Sweden,²² AF is increasing rapidly, and a rise in both incidence and prevalence is expected.^{20–22} It is estimated that every third person at the age of 55 with one elevated risk factor is at risk of developing AF.²³ Furthermore, the number of adults aged 55 and older with AF in the European Union is expected to double by 2060.²⁴ In addition to the ensuing suffering for many of those affected, this increase will have significant consequences from a health/economic perspective because AF is accompanied by many negative factors.

For those suffering from AF, it is not just the condition itself that causes problems; the associated risk of heart failure, ischemic stroke and premature death is high, and comorbidities are common.²⁵ AF can occur

at any age, but its incidence increases sharply with increasing age. Genetic causes, being of male gender and having European ancestry are factors that have been shown to increase the risk of AF.²⁶ Cardiovascular diseases such as myocardial infarction and heart failure also increase the risk of AF.⁸ Other contributing factors, which are often lifestyle related, include obesity, diabetes mellitus, sedentary lifestyle, obstructive sleep apnoea, smoking, hypertension^{26,27} and high levels of alcohol consumption.^{27,28} In fact, both insufficient^{8,27} and excessively vigorous physical activity^{8,29} can contribute to AF. In approximately 31% of first-detected new-onset AF, factors that provoke the occurrence are present. Such factors include pulmonary embolism, myocardial infarction, infection, and surgery among others.³⁰ Furthermore, AF is seen as a progressive condition, since many of those affected proceed from paroxysmal to non-paroxysmal AF. This progression is partly due to manageable risk factors.⁸

Management of atrial fibrillation

Studies in AF have shown that patients try to learn to manage the illness by themselves by identifying possible explanations for relapses and through repeated failures.^{1,3,31} In a study involving patients with paroxysmal AF, psychological stress emerged as the predominant self-reported trigger and was reported by more than half of the patients, followed by physical exertion, fatigue, alcohol and coffee intake.³²

Self-care is essential in AF because it permits affected patients to reduce the risk of recurrence and to manage and terminate an episode of AF by themselves. In this context, self-care involves different activities to improve health and limit and prevent illnesses, with or without help from healthcare professionals.³³ In the article 'A Middle-Range Theory of Self-Care of Chronic Illness' by Riegel et al., self-care is defined as 'a process of maintaining health through health promoting practices and managing illness',³⁴ (p.195) which I adhere to in this thesis. The theory includes three key concepts: self-maintenance, self-monitoring and self-management.³⁴ This can be described as patients taking various actions to maintain their emotional and physical stability, improve their well-being and preserve their health. By observing and listening to bodily changes, such as symptoms and signs, and checking blood pressure or glucose levels, patients can learn to assess their condition and determine whether action is needed.³⁴ Self-care activities have been shown to improve several outcomes, such as quality of life (QoL), self-efficacy and medication adherence.³⁵ In addition to reducing patients' symptom

burden and risk of relapse, managing risk factors for AF is also important because it can slow or reverse the progression of this condition.³⁶ Weight loss and risk factor management have been shown to reverse the condition of AF, reduce the symptom burden^{36,37} and lower the need for ablation.³⁶ Weight loss also lowers the risk of the recurrence of AF after an ablation.³⁸ Given these findings, lifestyle intervention and managing risk factors are essential.

The European Society of Cardiology (ESC) guidelines⁸ recommend the management of patients with AF according to the Atrial fibrillation Better Care (ABC) pathway. The 'A' in the ABC pathway refers to 'anticoagulation' and 'avoid stroke'. Since there is an almost fivefold higher risk of stroke in untreated AF patients,^{25,39} it is vital to start treatment with anticoagulants as soon as possible for those at risk. The most common treatment is a non-vitamin antagonist oral anticoagulant or a Vitamin K antagonist. By using the CHA₂DS₂-VASc score,⁴⁰ it is possible to detect those at risk for an ischemic stroke and in need of anticoagulation. However, the risk of bleeding and the patient's preferences must also be considered.⁸

The 'B' stands for 'better symptom control' with the help of rate- and rhythm-control strategies. Choices of treatment depend on factors such as symptoms, symptom burden, AF burden, rate, comorbidities, potential side effects, and patient values and preferences. A combination of different treatments for the rhythm-control strategy can be necessary, as it is necessary to restore and maintain the sinus rhythm; with the primary goal to reduce AF-related symptoms and improve HRQoL.⁸ Rhythm control can be important, since the progression of AF is associated with a deterioration in HRQoL.⁴¹ Rhythm strategies include electrical conversions, antiarrhythmic medications and catheter ablation. Both antiarrhythmic therapy and ablation have shown improved HRQoL, EHRA symptom score and decreased AF burden in patients with AF.⁴²

The 'C' refers to detecting and managing 'cardiovascular risk factors and concomitant diseases'. Since most cardiovascular risk factors are modifiable, identifying and managing these factors are important.⁸ Early diagnosis and treatment can be decisive in counteracting the development of AF.⁴³ In research, optimal levels of physical activity, a healthy diet, and lower BMI, blood pressure, total cholesterol and blood glucose are associated with a lower risk of AF.⁴⁴ Despite increased AF knowledge and the fact that the development of various treatments has

progressed, some patients do not feel well, report low HRQoL and find it difficult to live with and manage the disease.

The healthcare management of patients with AF in Sweden varies; most regions state that they are following some form of structured care but that there is potential for improvements.⁴⁵ There are indications that the care of patients with AF has been somewhat neglected. In a report from the Swedish Heart and Lung Association,⁴⁶ it appeared that a third of the patients felt that the healthcare system did not take their illness seriously. Furthermore, 40% thought they had not received sufficient information, only 10% had been offered education in AF and only 31% had met a specialist AF nurse.⁴⁶ That patients' experiences, symptoms, concerns and need of support are not always taken seriously, has been described in previous studies.^{1,3} The report from the Swedish Heart and Lung Association emphasises that patients with AF must be prioritised, and care needs to be improved.⁴⁶ More AF clinics are needed, with collaborative teams and specialist nurses that can meet patients' needs for support, self-care and lifestyle changes.

Nurse-led clinics are provided to support patients, most often after a post-acute period; they are run by qualified nursing professionals, who often have long experience of caring for this group of patients. Nurse-led clinics include assessments and evaluations, counselling/health education, treatments and procedures from a holistic perspective.⁴⁷ In Sweden, there is a relatively long tradition of nurse-led outpatient clinics supporting patients in managing their illness, for example for patients with diabetes⁴⁸ and heart failure.^{49,50} Nurse-led outpatient clinics for patients with AF have been implemented in Sweden. However, no studies evaluating these clinics could be found. Previous studies from other countries have shown that integrated AF nurse-led clinics can positively influence clinical outcomes and patient-reported outcomes (PROs) such as HRQoL,^{51,52} anxiety,⁵¹ depression,⁵¹ AF-related knowledge,⁵¹ healthcare utilisation,⁵² deaths^{52,53} and cost.^{52,54} In some studies,⁵¹⁻⁵⁴ but not all,⁵⁵ nurse-led clinics have reported better outcomes than usual care. However, since the results vary, more studies are needed.

The lack of patient-centred care and the importance of active patient involvement were highlighted in a previous study involving newly diagnosed patients with AF who felt that their visit focused solely on medical aspects and found it challenging to be involved in decision-making regarding their own care. The patients felt insecure about their AF both before and after the visit.⁵⁶ A great responsibility is placed on

individual patients to manage AF by themselves. In addition, studies in recent years have shown that modifiable risk factors such as obesity, smoking and high blood pressure are behind much of the risk of developing and worsening AF.²⁷ In collaboration with the patient, RNs can identify needs and opportunities and be a support in designing a plan for the implementation of for example lifestyle changes. Since patients' experiences vary and they have different needs, a more person-centred form of care is needed.

Person-centred care

In a review of PCC in patients with heart failure,⁵⁷ PCC was shown to improve QoL, symptom burden and self-efficacy. It was also found that PCC improved recovery, patients' dignity, and their mental and physical status.⁵⁷ According to Brännström and Boman, patients with severe heart failure who received PCC along with active heart failure care and palliative care had an improvement in their QoL and a significant reduction in morbidity.⁵⁸

PCC has been proposed by the Institute of Medicine Committee on Quality of Health Care in America as one of six specific aims to improve high-quality care.⁵⁹ Guidelines advocate a more patient-centred care that aligns with patients' needs and preferences, where patients play a central role in and are actively involved in decision-making.^{8,60,61} PCC is one of the six core competencies in the nurse's competency description in Sweden⁶² and is a concept used in many contexts. However, there is no clear agreed-upon definition of PCC and, in both the literature and health care, PCC is used interchangeably with 'patient-centred care', which can be confusing. While there are similarities between the two concepts, they differ in their goals: the goal of patient-centred care is a functional life, whereas that of PCC is a meaningful life.⁶³ The two concepts are similar in that both involve empathy, respect, engagement, relationship, communication, shared decision-making, a comprehensive and individualised approach, and coordinated care.⁶³ A 'patient' can be interpreted as someone who seeks and is under medical care due to an illness, getting treatment and meeting or communicating with a healthcare professional. In contrast, the word 'person' has a broader meaning that includes the individual's life and personal history i.e. the whole person.^{64,65} From my point of view, I see no conflict with using either of the two concepts. Many define the concepts similarly, but representatives of PCC place more emphasis on the person and non-medical needs. In some forms of care, it is viewed as inappropriate to talk about 'patients'. As mentioned in the introduction, I use both

‘person’ and ‘patient’ in this thesis, with the understanding that every ‘patient’ is also a ‘person’. When writing about persons and patients as groups, I often use the word people. Within PCC, it is emphasised that a patient is a person and should not be reduced to their illness, and the importance of knowing the person behind the patient is highlighted. In essence, PCC means involving the patient as an active participant in her own care and decision-making, instead of having the patient act as a passive target for various medical interventions.⁶⁶

There is a positive and increasing trend towards introducing PCC and patient involvement. However, transferring PCC into clinical practice can be challenging. In Sweden, a research centre for studies on PCC was created in 2010: the University of Gothenburg Centre for Person-Centred Care (GPCC). Inger Ekman, in concert with a steering committee, formulated and introduced three routines to simplify the implementation of PCC in daily practice.^{66,67} The first routine involves soliciting the person to contribute their narrative, where the narrative includes the person’s view of the disease and its impact on his or her life and is considered a basis for partnership. The second routine contains shared decision-making, including listening and sharing information between the person and healthcare professionals. The third routine involves the documentation of a health plan that includes the patient’s values, preferences, and beliefs and decision-making regarding treatments.^{66,67} Previous research has shown that PCC improves PROs such as QoL, symptom burden and self-efficacy.⁵⁷ In addition, PCC has been shown to reduce healthcare costs.⁵⁷ However, to the best of my knowledge, there has not yet been an evaluation of any nurse-led, person-centred clinic for patients with AF in Sweden.

Patient-reported outcomes

In addition to clinical outcomes, PROs are an important aid in reflecting the patient’s perspective on their own health and well-being; PROs can improve the interaction between the patient and healthcare professionals by improving communication and strengthening shared decision-making,⁶⁸ which facilitates PCC.^{69,70} PROs can also help in research to evaluate the effects of different treatments.^{70,71} PROs are defined as ‘any report of the status of a patient’s (or person’s) health condition, health behaviour, or experience with healthcare that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else’.⁷² A PRO can thus be used as both a primary and a secondary measurement. A patient-reported outcome

measure (PROM) is the instrument used (i.e. questionnaires and surveys).

In patients with cardiovascular diseases, the use of PROs and PROMs can lead to better-informed clinical decisions and can improve the quality of care.⁷³ Guidelines recommend their use,⁸ and their implementation in clinical practice is suggested.⁷³ To obtain more comprehensive information, a combination of generic, illness-specific and domain-specific PROMs can be used.⁷³ PROMs give patients the opportunity to express how they experience their situation, what they consider important, and how they perceive the illness and their HRQoL.

Health-Related Quality of Life

In literature, HRQoL has been defined in many ways;^{74,75} however, no single, accepted definition exists. The term HRQoL' is often used interchangeably with 'health' and 'QoL'.⁷⁵ To start with, the definition of the concept of health has developed over time, and various definitions have existed.⁷⁶ Further back in time, the focus was on the body's ability to function and health was seen as the normal state that could be affected by illness. In 1948, the World Health Organisation (WHO) proposed a new definition to link health to well-being more clearly, and health was defined as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.⁷⁷

In 1992, Lindström considered health to be a problematic concept because it was closely associated with disease and instead wanted to link health to QoL.⁷⁸ Lindström synthesised the concept of QoL as a general framework with the definition 'quality of life is the total existence of an individual, a group or a society'.⁷⁸ (p.303) The definition was intended to be broad in order to include people's experience of QoL and to make room for interpretations from different disciplines.⁷⁸ In 1993, the WHO further developed the definition of QoL, defining it as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'.⁷⁹ (p.153) The concept of QoL is comprehensive and is influenced by factors such as a person's physical health, mental state, social relationships, relationship with their environment, and degree of independence.⁷⁹ However, even if Lindström's, and later WHO's definitions were broad, there still exists other definitions of the concept.⁸⁰

Distinguishing between the concepts of 'Health', 'QoL' and 'HRQoL' presents challenges. However, HRQoL encompasses health and daily life concerns, including biological functioning, health perceptions, symptoms, functional status, and overall quality of life.⁸¹ The concept of HRQoL relies on individuals' subjective assessment of how a disease and its treatment impact their health status.⁸² Since this thesis aims to explore patients' experiences with AF, including how AF and its treatment affects their HRQoL, the concept of HRQoL will be used throughout in this thesis.

Previous studies have shown that HRQoL in patients with AF is impaired compared with the general population,^{83,84} healthy controls and patients with other heart diseases.^{84,85} Since improving HRQoL is an important goal in treating patients with AF,⁸ it is essential to determine factors that affect HRQoL. Symptom severity,⁸⁶ anxiety and depression⁸⁵ are well known to negatively affect HRQoL. Lower education,⁸⁷ female sex and younger age (age <60, <65 respectively),^{87,88} new-onset AF and comorbidities have been shown to correlate with lower HRQoL.^{88,89} Furthermore, the treatment burden is associated with impaired HRQoL.¹⁶ Ablations^{42,90} and rate- and rhythm-control medications⁴² have been shown to improve HRQoL in some patients but not all.^{42,90} Preventing risk factors can reduce and reverse the progression of the condition, decrease symptoms³³⁷ and improve QoL.⁹¹ Studies regarding the effect of illness perceptions on HRQoL in patients with AF are sparse. However, in diseases such as myocardial infarction⁹² and psoriasis,⁹³ illness perceptions has been shown to have both positive and negative effects on HRQoL.^{92,93}

Illness perceptions

Illness perception refers to how a person perceives and makes sense of an illness or a health threat.^{94,95} A person's understanding of her illness depends on her previous experiences and includes structured beliefs about a health condition's symptoms, consequences, duration, controllability and causes.⁹⁶ These perceptions have been shown to predict different psychosocial and clinical outcomes across different diseases. Research suggests that more pronounced negative illness beliefs correlate with unfavourable outcomes, while positive beliefs are linked to better overall outcomes.⁹⁷ When patients have negative perceptions about their illness – for example, they may associate many symptoms and more severe consequences with the illness – it may slow

the recovery process and increase future disability, independent of the severity of the condition.⁹⁶

Five often mentioned dimensions of illness perception are the *identity* (symptom and name of illness); *timeline* (duration and pattern of the illness); *cause* (beliefs about causes of illness); *consequences* (consequences due to the illness and how it will affect the individual physically, psychologically and socially); and *control* (beliefs about to the degree to which the illness can be prevented, treated or cured).^{94,95} Illness perceptions can be measured via questionnaires.⁹⁸⁻¹⁰⁰ In some of the studies in this thesis, the Revised Illness Perception Questionnaire (IPQ-R)⁹⁹ and the Brief Illness Perception Questionnaire (B-IPQ)¹⁰⁰ are used. These are based on Howard Leventhal's theory of the Common-Sense Model of Self-Regulation (CSM), which will be used to understand and interpret the results of illness perception in this thesis.

Common-Sense Model of Self-Regulation

The CSM is a theoretical conceptual framework that aids in understanding how people perceive, interpret, react and adapt to an illness or health threat.^{95,101,102} A person exposed to a health threat (i.e. symptoms, manifest illness) will try to understand the threat by forming cognitive beliefs. These beliefs are influenced by the person's emotional response and will determine how that person will respond to and manage the illness.^{95,102}

CSM involves three steps, each involving cognitive and emotional responses towards the threat. During the first step, illness perceptions are developed by the person to understand the illness or health threat. Symptoms act as key determinators and initiate the self-regulation process. The perceptions of the symptoms are guided by the person's past experiences, social and cultural factors, and the environment. Illness perceptions also include emotional reactions such as fear and anger towards the illness or threat.^{101,102} In step 2, the person's strategy or action regarding how to cope with the illness or health threat starts. The person's perception of and emotions about the illness or health threat greatly influence how that person acts and copes with it.^{101,102} During the third step, the person assesses whether the coping strategies have succeeded or failed. If the initial efforts fail to control the health threat, the problem and management plan will be re-evaluated. This process is dynamic and self-regulating.^{101,102}

Illness perceptions in patients with atrial fibrillation

Research on illness perceptions in people with AF is still relatively sparse.¹⁰³⁻¹⁰⁶ Lane et al. reported that improvement in physical health over a 12-month period was slowed by the number of symptoms the patients attributed to AF.¹⁰⁴ McCabe et al. found that a stronger belief in AF as unpredictable and recurrent, having severe consequences and being psychologically caused was linked to more negative emotions. In addition, those who had a better understanding of AF reported fewer negative emotions related to AF.¹⁰⁶ People who develop AF are affected differently by the disease. Some experience no symptoms, while others suffer and are greatly limited.⁸ The symptoms can also vary over time in the same individual. The reason for the symptomatology is not fully understood, however both physical and psychological factors are believed to contribute.⁶ A person's perception of an illness (symptoms) has been shown to contribute to how they feel, react to and manage the illness,^{96,107} and more studies are needed in this area, especially on the effect of illness perception on HRQoL.

Rationale

The literature shows that living with and managing AF can be complex, and patients have a strong need for someone to turn to and receive support from. As mentioned earlier, symptoms vary in those affected and may range from no symptoms to an extensive symptom burden. HRQoL for people with AF is often poor and partly related to their symptom burden. Identifying factors that can influence HRQoL and patients' symptom burden is therefore essential. Studies have shown that the patient's perception of an illness can affect HRQoL. Only a few studies exist on illness perception in patients with AF, and there are even fewer studies on the effects of illness perception on HRQoL. There is also a lack of research on whether newly diagnosed patients differ in their experiences, compared with those who have lived with AF longer, and how this difference may change over time. Such knowledge can increase the understanding of how patients are affected at different stages in the disease trajectory and if and when various interventions should be implemented. Since the condition is complex and people are affected by it differently, nurse-led clinics can support patients in managing AF. In general, nurse-led clinics have shown some positive results; however, there are conflicting results, and more research is needed.

As there is limited research on AF from a patient perspective, it is essential to further investigate patients' experiences of AF and whether their experience changes over time. Such knowledge can enable improved customised care. An evaluation of an implemented nurse-led, person-centred clinic could show whether HRQoL, AF symptom burden, anxiety and depression symptoms, and illness perceptions in patients with AF improve with support from nurses.

Aims

The overall aim of this thesis was to explore patients' experiences of AF and to evaluate the effects of a nurse-led, person-centred clinic.

The specific aims of the studies were as follows:

Study I: To explore the experiences of living with symptomatic AF.

Study II: To describe illness perceptions and HRQoL in women and men with AF, and to explore the relationship between illness perceptions and HRQoL in patients with AF.

Study III: To compare patient-reported outcomes in patients newly (<6 months) diagnosed with AF with those who have had a longer diagnosis (≥ 6 months) and to investigate whether or not these outcomes change over a 6-month period.

Study IV: To evaluate the effects of a nurse-led, person-centred clinic on patient-reported outcomes in patients with AF.

Materials and Methods

This thesis combines qualitative and quantitative methods. An overview of the studies is presented in Table 1.

Table 1. Overviews of the study designs, data sources, participants and analyses in Studies I–IV

Study	Design	Data sources	Participants	Analysis
I	Exploratory, descriptive	Interviews	15	Qualitative content analysis
II	Cross-sectional	Questionnaires	167	Quantitative descriptive, comparative, correlation, regression statistics
III	Longitudinal	Questionnaires	129	Quantitative descriptive, comparative, statistics
IV	Randomised controlled trial	Questionnaires	103	Quantitative descriptive, comparative, statistics

Settings

Studies I–III were performed using data collected from patients with AF at a cardiology clinic at a university hospital in Sweden. The participants consisted of patients with AF who were admitted and scheduled for a cardioversion. Study IV was performed with data collected from patients with AF in a randomised controlled trial at a cardiovascular outpatient clinic at a university hospital in Sweden.

Participants

The inclusion criteria for study I-III were a diagnosis of AF, Swedish speaking, aged 18 years or older, and the ability and willingness to fill in questionnaires and participate in interviews.

In Study I, 15 patients with symptomatic AF from the survey study participated. To gain a broad range of experiences, a purposeful sampling was conducted regarding gender, age and number of years with AF (where the latter ranged from 6 months to 10 years). The participants included six women and nine men with a median age of 70.

In Study II, 167 patients participated. Of the 180 who agreed to participate, 13 were excluded due to either misdiagnosis (n=5) or for administrative reasons; that is, failure to complete or return the questionnaires (n=8) (Figure 1). The participants had a mean age of nearly 69 years; 69% were men, and 38% had a university or college education. Furthermore, 38% were living alone and 28% were still working. The participants had had the diagnosis of AF for a median time of 19 [1, 74] months. Of the participants, 60% had hypertension, 24% had heart failure and 18% had diabetes.

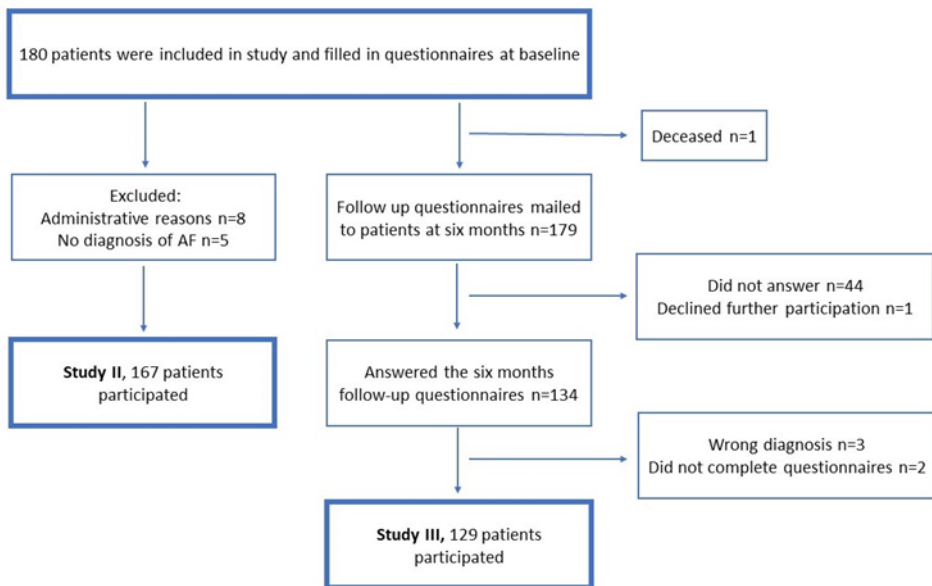


Figure 1. Flow chart for Studies II–III

In Study III, 129 patients participated. Of the 180 patients participating at baseline, follow-up questionnaires were sent to only 179 because one

had deceased. Of the 179 participants, one declined further participation, and 44 did not return the questionnaires, resulting in a response rate of 75%. Five of the 134 respondents were excluded due to wrong diagnosis (n=3) or not having completed the questionnaires (n=2) (Figure 1). Of the remaining participants, 25% had heart failure, 21% had diabetes and 18% had coronary artery disease. The mean age of the total group was nearly 71 years; 67% were men, 40% had a university or college education, 19% were still working and 22% were living alone.

For Study IV, the inclusion criteria were being 18 years or older, diagnosed with AF, having been referred to the outpatient clinic after contact with healthcare due to AF, and being willing to participate and complete questionnaires. Participants were excluded if they were referred to a physician due to AF; had an atrial flutter diagnosis or heart failure corresponding to NYHA IIIB-V in connection with the care contact; had had heart surgery less than 3 months before the care contact; were waiting for an ablation or heart surgery; or had developed AF in connection with a myocardial infarction or infection. Finally, participants were excluded if they were unable to fill in the questionnaires.

In Study IV, of 174 available patients, 105 were included; 52 were randomised to the (nurse-led) intervention group and 53 to a control group (care from physician). Of the 52 participants in the nurse-led group, two patients withdrew their participation. (A flowchart for the study is provided in Figure 2.) Of the 103 patients that finally participated, 64% were male, the mean age was 68 years, 28% lived alone, 84% had high school or higher education, 36% were still working, and the median time since AF diagnosis was 15 [9, 89] weeks.

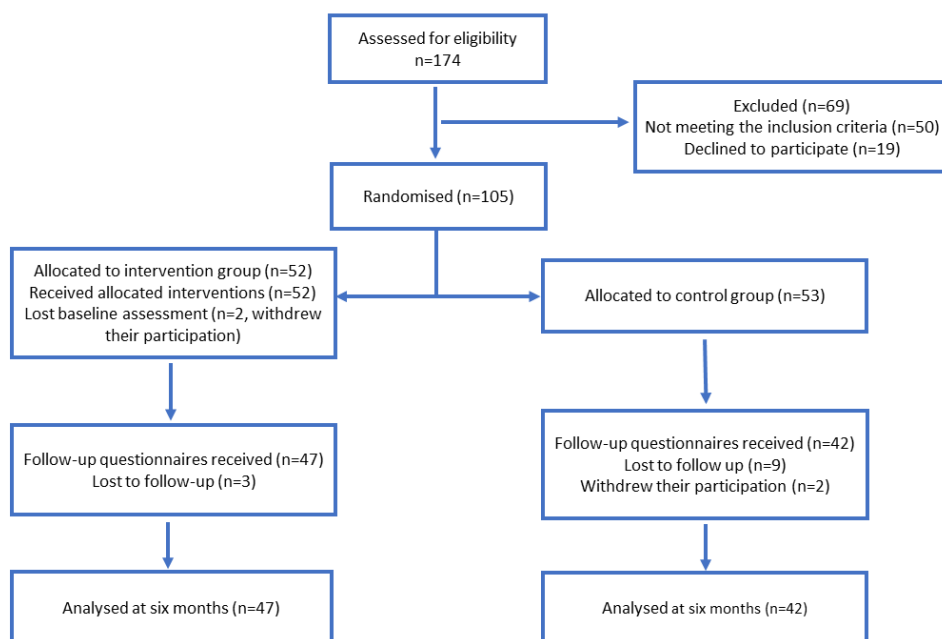


Figure 2. Flowchart for Study IV

Data collection and procedure

In Study I, individual, semi-structured interviews¹⁰⁸ were conducted between June 2018 and April 2019 by two RNs with PhD degrees and experiences in interviewing and two RNs who were under specialist training. According to each participant's wishes, the interviews were held either in a quiet, secluded room at the hospital or in the participant's homes. Interviews were held using an interview guide developed by three of the research team members. The questions focused on experiences of living with AF, how the respondents managed AF, the respondents' participation in and opportunity to influence their care, their perception of the illness, and their future expectations. Follow-up questions such as 'Can you describe more?' were used to obtain a deeper understanding of the participants' experiences. The digitally recorded interviews lasted for 20–40 minutes and were transcribed into text.

Participant recruitment for Studies II–III was conducted between March 2018 and March 2020. Patients scheduled to undergo electrical cardioversion were consecutively asked to participate. Patients who agreed after receiving oral and written information and who met the inclusion criteria were included in the study and completed self-reported

questionnaires. After 6 months, a second questionnaire was sent to the patients' home by mail. The questionnaires used for each study (II and III) are described in Table 2. Additional information on comorbidities and clinical data were obtained from the questionnaires and the patients' medical record.

For Study IV, the recruitment and randomisation procedures were conducted between October 2020 and May 2023. The collection of data continued until December 2023.

The RNs at the clinic informed the research team about the patients who were referred for a follow-up because of AF. The patients were then contacted by phone and informed about the study. Those who met the criteria for participating in the study were asked to provide written consent. After obtaining written consent, the patients were randomised into either the intervention group (nurse-led care) or the control group (follow-up by physicians). The randomisation was performed using a block randomisation of 10 with a 1:1 ratio. In the randomisation process, which was carried out with the help of people outside the research group, sealed opaque envelopes were used.

After the randomisation, the patients were offered follow-up appointments based on normal routines at the clinic. Before the visit, they filled in questionnaires; then, 6 months after the visit, questionnaires were sent to the patients' home. The questionnaires used for Study IV are described in Table 2. None of the research group members worked as a nurse at the nurse-led clinic, and the person who analysed the results was blinded to the patient allocation. The study flow is illustrated in Figure 2.

Intervention

Nurse-led care

A nurse-led clinic for patients with AF was introduced in 2019. Prior to the clinic's implementation, RNs with extensive experience in cardiac care, lifestyle changes and patient education had received training on AF, its treatments and its management by cardiologists at the clinic. The nurses had also received training in PCC on three occasions, partly based on the GPCC model.^{66,67} The meetings included lectures and discussions. In the first meeting, the cornerstones of PCC and the concept of 'patient versus person' were discussed. In the second meeting, the relationship

between patient and caregiver was emphasized, and cases were discussed. At the third meeting, the importance of patient narratives, the patient-healthcare professional partnership, and the documentation of a health plan were discussed. Follow-up meetings with lectures and discussions followed the three occasions.

Patients in the intervention group were offered a visit to RNs at the clinic within approximately 4 weeks; the visit lasted for about 60 minutes. Before the visit, the patients completed the B-IPQ,¹⁰⁰ which identifies the patient's perception of the illness based on nine questions. The questionnaire results, along with the patient's narratives, were used as a basis for further discussions to identify each patient's need for support, such as the need for information about AF, self-care and lifestyle changes. The B-IPQ questionnaire facilitated a person-centred approach. The visit included discussions about risk factors, lifestyle changes, symptoms and self-care, as well as medications and their effects and side-effects. Goals were formulated in a health plan in consultation with the patient based on the patient's narrative, preferences, resources and risk factors. Custom medical record notes in the computer medical record system documented the visit and the patient's personal health plan. The health plan was printed and handed to the patient after the visit. This approach was taken to improve patients' participation in their care, as recommended in a person-centred approach.⁶⁶ The visit also included measurements such as ECG, blood pressure, height, weight and CHA₂DS₂-VASc score. Once a week, the RNs were supported by a prespecified group of cardiologists with, for example, medical questions and possible continued planning. Most patients received follow-up phone calls or new visits as needed.

Control group

The control group visited a physician, who was usually in training and supervised by a cardiologist. The visits were scheduled within 4–6 weeks and lasted approximately 45 minutes. The visit included discussions about medications, side effects, symptoms, risk factors and information about the illness. The visit also included ECG, blood pressure, height, weight and CHA₂DS₂-VASc score measurements and a physical examination. Some patients had follow-ups at the heart clinic, while most were referred to their primary care physician.

Questionnaires

Table 2 provides an overview of the questionnaires used for Studies II-IV, and Table 3 shows the scales used and the meaning of higher scores.

Table 2. Overview of the questionnaires used in Studies II–IV

Questionnaires	Study II	Study III	Study IV
Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia (ASTA)	X	X	X
Brief Illness Perception Questionnaire (B-IPQ)			X
EuroQol-5D-3L (EQ5D) and EQ-VAS	X		X
Hospital Anxiety and Depression Scale (HADS)		X	X
Revised Illness Perception Questionnaire (IPQ-R)	X	X	

Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia

The Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia (ASTA) is an arrhythmia-specific questionnaire that measures symptoms, symptom burden and HRQoL in patients with arrhythmias.^{109,110} It was developed and validated in Sweden and later translated and validated into several languages.

The questionnaire is divided into three separate parts. Part I evaluates the patient's latest episode of arrhythmia and current medication. Part II assesses the symptom burden and consists of a nine-item symptom scale with a 4-point response scale. The four response alternatives range from 0 (*No*) to 3 (*Yes, a lot*). Higher scores entail a higher symptom burden. Part II also consists of questions, as follows: the frequencies of arrhythmia during the last 3 months, the average and the most extended duration of an arrhythmia episode, experiences of arrhythmia, whether the arrhythmia is triggered on special occasions, and experiences of being close to fainting or having fainted in association with arrhythmia.¹⁰⁹

Part III assesses HRQoL using a 13-item scale, with the same response alternatives as in the symptom scale. Higher scores imply that AF has a more negative impact on daily life. The ASTA HRQoL scale can be

divided into a physical (7-item) and a mental (6-item) subscale. Scale scores can be calculated for the symptom scale and HRQoL scales. For the symptom scale, scores can be calculated if at least eight out of nine items are completed and for the HRQoL total scale if at least 11 of 13 items are completed. For the physical and mental subscale, scores can be calculated if there is only one missing item. The different scales are then calculated, with each ranging from 0–100. Higher scores mean a higher symptom burden and worse HRQoL due to the arrhythmia.^{109,110} In Studies II-IV, Cronbach's α for the ASTA scales used ranged between 0.75 and 0.91.

Brief Illness Perception Questionnaire

The B-IPQ¹⁰⁰ is a validated, generic questionnaire for measuring illness perceptions. The questionnaire is a shorter and more simplified questionnaire compared to the IPQ⁹⁸ and the IPQ-R.⁹⁹ The questionnaire consists of nine items. The first eight items are assessed on an 11-point response scale, from 0 to 10. Items 1–5 consider cognitive representations: *consequences* (degree of consequences attributed to illness); *timeline* (the person's perception of how long the illness will last); *personal control* (feeling of having control over the illness); *treatment control* (belief that the treatment will control/cure the illness); and *identity* (degree of symptoms attributed to the illness). Items 6 and 8 assess emotional representations: *concern* (to what degree the illness concerns the person); and *emotion* (the impact of the disease emotionally; e.g. anger, depression). Item 7 covers *illness coherence* (how well the person makes sense of her illness). Higher scale scores mean a higher perception of the concept measured.

Items 1–8 assess one dimension of each type of illness perceptions. It is possible to compute an overall score by reversing items 3, 4 and 7 and adding this to the other five items. The scoring will be between 0–80, with higher scores reflecting the illness being perceived as more threatening.¹⁰⁰ In study IV, the dimensions were used separately. Item 9 covers causal factors and is an open question with the option to list three possible reasons for the illness. The answers can be grouped into categories based on the illness being studied, and categorical analysis can then be carried out.¹⁰⁰ Item (dimension) 9 was not used in study IV.

EuroQol-5D-3L and the EuroQoL-Visual Analog Scale

EuroQol-5D-3L (EQ5D) is a validated, generic questionnaire for measuring HRQoL. The questionnaire consists of a descriptive part and a visual analogue scale (EQ-VAS).^{111,112} The descriptive part consists of

five questions corresponding to the five dimensions of health: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. For each dimension, there are three option levels ranging from 1 (*no problems*) to 3 (*extreme problems*). The scale scores can be calculated into an EQ-5D index score with the use of a country-specific value set with the anchor points 0 (*death*) to 1 (*full health*). In our studies, we calculated a EQ5D index using a value set for the UK.¹¹³ The EQ-VAS consists of a 20-cm vertical scale in which the person rates their current overall HRQoL. The scale ranges from 0 to 100, where 100 represents the best and 0 the worst imaginable health state.¹¹¹

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a validated questionnaire that aims to assess symptoms of anxiety and depression in non-psychiatric patients.¹¹⁴ It has been translated and validated in a Swedish context.^{115,116} The questionnaire consists of 14 items, with a four-response scale for each item ranging from 0 to 3. All responses are summed into two subscales, HADS-A and HADS-D, and each subscale is scored between 0 and 21. Higher scores indicate more symptoms of anxiety and depression. Recommended cut-off scores are ≥ 8 , which may indicate symptoms, and ≥ 11 for probable symptoms of anxiety and depression.¹¹⁴ Cronbach's α varied between 0.78 and 0.92 for HADS-A and HADS-D used in Studies III and IV.

Revised Illness Perception Questionnaire

IPQ-R⁹⁹ is a validated and generic questionnaire that contains questions or statements about the patient's illness perceptions. It has been translated and validated into several languages, including Swedish.¹¹⁷ The IPQ-R consists of three question areas. The first area measures the *Identity* of the illness and consists of 14 general symptoms. The patients are asked if they have the symptom and then whether they attribute the symptom to their illness. In the second area, patients respond to 38 questions about their cognitive perceptions and emotions regarding the illness using a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*). The 38 questions are then divided into seven scales: *timeline acute/chronic*, *timeline cyclical*, *personal control*, *treatment control*, *emotional representations*, *illness coherence* and *consequences*. The last area covers patients' perception of the *causes* they attribute to the illness and consists of 18 statements about probable causes. The patients answer using a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*).⁹⁹ Cronbach's α varied between 0.67 and 0.89 for the scales used in Study II and III.

Table 3. Scales used in the studies and the meaning of a higher score

Scales	Meaning of higher scores
The Arrhythmia Specific Questionnaire in Tachycardia and Arrhythmias (ASTA)	
ASTA symptom	Higher symptom burden due to arrhythmia
ASTA HRQoL total	Worse HRQoL due to arrhythmia
ASTA HRQoL phys.	Worse physical HRQoL due to arrhythmia
ASTA HRQoL ment.	Worse mental HRQoL due to arrhythmia
EuroQoL-5D-3L (EQ5D) & EuroQoL-VAS	
EQ5D index	Better HRQoL
EQ-VAS	Better HRQoL
The Brief illness Perception Questionnaire (B-IPQ)	
Consequences	Perceive more negative consequences due to illness
Timeline	Higher belief that the illness will last long
Personal control	Higher belief in the ability to control the illness
Treatment control	Higher belief in treatment's ability to control/cure illness
Illness identity	Perceive more symptoms due to illness
Concern	Perceive more concerns due to illness
Illness coherence	Higher perceived comprehensibility of the illness
Emotional representations	More negative emotions attributed to the illness
The Hospital Anxiety and Depression Scale (HADS)	
HADS-Anxiety	More symptoms of anxiety
HADS-Depression	More symptoms of depression
The Revised Illness Perception Questionnaire (IPQ-R)	
Illness identity	Perceive more symptoms due to illness
Timeline acute/chronic	Higher belief that the illness will last long
Consequences	Perceive more negative consequences due to illness
Personal control	Higher belief in the ability to control the illness
Treatment control	Higher belief in treatment's ability to control/cure illness
Illness coherence	Higher perceived comprehensibility of the illness
Emotional representations	More negative emotions attributed to the illness
Timeline cyclical	Higher belief in the illness as cyclical, recurrent

Analysis

Qualitative content analysis

As the aim of Study I was to describe experiences, a qualitative content analysis with an inductive approach, after the work of Graneheim and Lundman, was used to analyse the transcribed interviews.¹¹⁸ This approach focuses on the manifest part of the text and interpretation of the latent content.^{119,120}

The analysis was performed in several steps. First, the entire interview text was read to acquire a basic understanding of the content. The next step entailed de-contextualising.¹²⁰ Text corresponding to the aim of the study was identified, divided into meaning units and condensed (i.e. shortened while retaining the core message). The condensed meaning units were then interpreted and labelled with codes.¹²⁰ Then, the next step, the re-contextualisation part of the analysing process began.¹²⁰ Based on similarities and dissimilarities, codes were sorted and abstracted into six subthemes. Subthemes with similar content were interpreted and abstracted into three themes and then further interpreted into an overall theme. Interpretation is a crucial part of the re-contextualisation process, as it involves transitioning from descriptions of the manifest content to nuanced interpretations of the latent content.¹¹⁹ Throughout the analysis process, the researchers continually switched between the whole text and specific parts of the text, with discussion until a consensus was reached regarding the results.

Statistics

For Studies II–IV, all statistical analyses were performed using SPSS 28 (IBM Corp, Armonk, NY, USA). The normality of the data was assessed using the Shapiro-Wilk test and Q-Q plots. Categorical data were presented using counts and/or percentages. Continuous data were presented either with medians with quartiles [Q1, Q3] or an interquartile range (IQR) or means with SD. To compare proportions between groups, the Chi-square test or the Fisher's exact test was used. To measure the internal consistency for the different scales, Cronbach's α coefficients were used. A two-tailed $p < 0.05$ was considered significant for all statistical tests.

In Study II, because of skewness in data, we used the Mann-Whitney U test when comparing women and men in the univariate analyses of IPQ-R subscales and HRQoL. To determine the direction and power of

association between the ASTA HRQoL total scale and the IPQ-R subscales and age, a Spearman correlation analysis was conducted. We then performed a multiple linear regression analysis to investigate whether the IPQ-R subscales (Illness identity, Consequences, Emotional representations, and Timeline cyclical) that were significant in the correlation analysis were independently associated with the ASTA HRQoL total scale. The model also included sex as a variable. Before the analysis, a square root transformation was performed on the ASTA HRQoL total scale to mitigate problems due to skewness. No multicollinearity was observed between the independent variables in the multiple linear regression analysis.

In Study III, to assess differences between newly diagnosed and previously diagnosed patients with AF and because of non-normal data, the Mann-Whitney U test was used for continuous data. For paired and repeated measures within groups, the Wilcoxon signed-rank test was used for continuous data and McNemar's test was used for categorical data. In the nine items for ASTA symptoms, the four-response option was categorised as "Yes" if the respondent had symptoms and "No" if not.

In Study IV, which was a randomised controlled trial, a power analysis was performed in the planning stage. The calculation was grounded on the following assumptions: the difference was assessed using a two-sided t-test between groups, with a significance level of 5%. In addition, based on previous collected data, a standard deviation of 18 was assumed for the EQ-VAS measurement. The analysis indicated that 52 people were required in each group to detect an absolute difference of 10 units between groups, as measured by EQ-VAS (0–100), at baseline and 6 months. The analyses for Study IV were conducted following the intention-to-treat principle, which means that all available data were utilised based on the initial allocation, regardless of the level of attendance. To assess differences between the intervention and the control group in this study, the Mann-Whitney U test was used for continuous data and the Chi-square test was used for categorical variables. In the within-group analysis over time, the Wilcoxon signed-rank test and McNemar's test were respectively used for continuous and categorical data.

Missing items

Some of the analyses in Studies II, III, and IV were based on the sum scores of several items in the questionnaires; therefore, unfilled items were internal missing data for the respective variable. Missing items in Studies II–IV were handled according to the guidance provided by the developers of the ASTA and IPQ-R questionnaires and were replaced based on the individual participants' means for the different subscales. In the subscales of the IPQ-R, one item was replaced in subscales with four or five items and up to two missing items were replaced in subscales with six items. In the ASTA HRQoL subscales (in Studies II–IV) and in the ASTA symptom scale (Studies III and IV), only one item was replaced in each subscale. In the ASTA HRQoL total scale, only one item was replaced in Studies II and IV, and up to two items were replaced in Study III. Missing data in HADS were replaced only in Study IV and were based on the mean value of the individual's scale,¹²¹ only being replaced when one item was missing in either HADS-A or HADS-D. If more were missing, they were not replaced and became missing. Missing values in the EQ5D index, VAS, illness identity (IPQ-R) and B-IPQ scales were not replaced.

Ethical considerations

All studies included in this thesis followed the principles in the Declaration of Helsinki.¹²² Before participating, patients gave their informed and written consent. They were informed that they could – without explanation – withdraw their participation at any time. The Declaration of Helsinki emphasises that “Every precaution must be taken to protect the privacy of the research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity.”¹²² (p. 2192) All sensitive information concerning the participants was handled confidentially. The questionnaires and the recorded and transcribed interviews were assigned code numbers and kept locked and separate from the code lists with the corresponding names.

Participating in interviews and completing questionnaires cannot be considered to risk causing harm or pain to the participants. However, reflections and conversations about illnesses and experiences can arouse emotions and cause discomfort. In addition, there is always a risk that privacy is perceived as threatened. The study participants were given the opportunity to contact the research team if there was need for support. If

further support had been needed, the patient would have been referred to a nurse or counsellor at the outpatient clinic at the hospital.

Ethical approval was obtained from the regional Ethical Review Board, Umeå, Sweden, for Studies I–III (No. 2018-24-31M) and for supplementary application (No. 2018/151-32). A supplementary application for Studies I-III were also obtained from the Swedish Ethical Review Authority (No. 2021-06734-02). Ethical approval for Study IV was obtained from the Swedish Ethical Review Authority (No. 2020-02425).

Results

Balancing life

Study I aimed to explore patients’ experiences of living with symptomatic AF. The analysis resulted in a main theme, Balancing life, which encompassed three themes with further subthemes (Figure 3). The main theme comprises the diverse efforts made by participants to handle the complexities of their life situations. It reflects how they try to comprehend and manage life with AF, describing their various attempts to navigate a fragmented care system and their efforts to cope with the challenges of inadequate information, support and participation in their care. Their narrative includes their struggle to maintain normalcy in their lives despite the illness and its alterations to their self-image.



Figure 3. Main theme, themes and subthemes

Striving for illness control

The participants described their experience as a process that occurs over time and their desire and attempts to keep life as normal as possible. Their experiences of symptoms varied, for some, the initial symptom appeared suddenly, others described vague sensations, more like a feeling of discomfort. They explained how they first tried to understand that they were ill and then to figure out what could have caused the illness. Some created theories, based on their own experiences and lifestyle, and thought that the symptoms were caused by stress or mental exhaustion. Some thought that exercise would protect them and, when they got symptoms, they increased their exercise. The unpredictable symptoms and the illness's association with the heart created anxiety, especially early in the illness trajectory. The use of antithrombotic drugs also created anxiety. Most participants refrained from confiding their anxieties to others and instead attempted to manage them on their own. For many, anxiety was often more challenging to manage than the physical symptoms, particularly when the anxiety occurred at night or for participants who lived alone. Some believed that emotions such as anxiety and stress could worsen their AF and, because the AF itself caused anxiety, they attempted to remain calm. Some coped by rationalising their symptoms or engaging in self-soothing techniques. One participant talked to her heart at night to cope with her anxiety.

Participants described how they had learned over time to understand what could trigger AF and, through repeated attempts and failures, how to deal with recurrent attacks. To gain control, some used prescribed medication and some bought monitors for checking their heart rate; others made lifestyle changes. Physical symptoms could change and often became less severe, and their anxiety level decreased over time. Having confidence in the healthcare system was of great importance.

Becoming a receiver or an active partner in care

The participants had varying experiences of receiving information. Although they were generally treated well by physicians, the information they received was mostly about the recommended medication and its importance. To get a more comprehensive understanding of AF, almost all the participants searched on the Internet. Many participants expressed a desire to have someone to discuss their thoughts with. For example, they wanted to discuss lifestyle-related issues and get advice. The participants' desire to be involved in their care varied. Some wanted the physician to make all the decisions and decide for them. Others

became more experienced, as time went by, and were actively involved in decision-making about medication, ablation and care planning. Being involved in their own care and having a plan contributed to a sense of hope. Some participants understood the importance of having knowledge and being engaged in their care because – due to multiple illnesses – they had experienced a lack of coordination between clinics. For those having difficulty accepting an ablation or a pacemaker, being involved in care planning gave them time to get used to the idea.

Dealing with changed self-image

Because AF is a condition that usually recurs, the participants' physical ability varied over time. They reported having difficulty with how the unpredictable attacks of AF affected them and with the sudden feeling of weakness, especially for those who usually saw themselves as strong. Some had previously perceived illness as a sign of weakness; now, their image of themselves changed. The attacks not only affected them physically and psychologically but also led to negative social consequences, which led to difficulties in planning their life. For some the symptoms elicited feelings of inferiority, prompting the avoidance of certain activities.

As time went on, the participants realised that AF was chronic, and they had to accept their life changes and live with uncertainty. They learned to cope with attacks and to accept treatments. The participants described how they have had to accept their care dependency and noted that they appreciated meeting the same professional team with extensive knowledge and effective management when it occurred.

Illness perceptions and Health-Related Quality of Life

The results of Study II showed that the women, compared with the men, had worse HRQoL within the ASTA physical subscale (mean score, 37.1 vs. 29.6, $p=0.047$) and EQ-VAS (mean score, 63.1 vs. 69.5, $p=0.044$). Furthermore, the women reported lower mean scores in the IPQ-R, personal control subscale (17.5 vs. 18.7, $p=0.039$), suggesting that they had less confidence in their ability to control AF than the men. Both women and men on average reported between four and five symptoms caused by AF. The most common symptom was reduced physical ability ($n=120$), followed by shortness of breath ($n=110$) and fatigue ($n=103$). Regarding symptoms that were not usually considered symptoms of AF, some of the patients experienced associations such as stiff joints ($n=14$), red eyes ($n=5$) and a sore throat ($n=3$).

A correlation analysis showed that the more symptoms and consequences the patients attributed to the illness, the worse their HRQoL (IPQ-R subscales; illness identity $r=0.658$, $p<0.001$, and consequences $r=0.509$, $p<0.001$). The results also showed that the greater the participants' emotional responses, such as anxiety or anger, and the more they experienced AF as cyclical, the worse their HRQoL (IPQ-R subscales; emotional representations $r=0.449$, $p<0.001$, and timeline cyclical $r=0.302$, $p<0.001$).

A multiple linear regression model (Table 4) was conducted to examine factors associated with ASTA HRQoL. The results of the analysis showed that stronger illness identity (more symptoms), higher consequences (AF effect on daily life), greater emotional representations (anger, anxiety or depression attributed to AF), and higher timeline cyclical (perceiving AF as recurrent) were all associated with poorer HRQoL.

Table 4. Multiple linear regression model of factors associated with the ASTA HRQoL total scale

Variables	B	95% CI	P
(Constant)	-1.413	-2.789– -0.038	0.044
Illness identity	0.495	0.378–0.613	<0.001
Emotional representations	0.079	0.016–0.142	0.014
Consequences	0.071	0.007–0.135	0.031
Timeline cyclical	0.087	0.013–0.162	0.022
Sex	0.360	-0.162–0.881	0.175

$R^2=0.574$, Adjusted $R^2=0.558$, $F=34.819$

Differences in patient-reported outcomes between newly diagnosed patients and those previously diagnosed

At baseline, the results for IPQ-R showed that newly diagnosed patients reported AF as cyclical (recurrent) to a lesser extent (11.2 vs. 12.6, $p=0.019$) and as chronic to a lesser extent (19.5 vs. 22.4, $p=0.003$) compared with patients who had an earlier diagnosis. Newly diagnosed patients scored higher in personal control (19.7 vs. 17.9, $p=0.004$) and treatment control (18.6 vs. 17.6, $p=0.041$) than those with an earlier diagnosis, suggesting that newly diagnosed patients had a greater belief

in their own ability and the treatment they received to control AF. A higher proportion of newly diagnosed patients reported more symptoms of anxiety (HADS-A ≥ 8) than previously diagnosed patients (25% vs. 10%, $p=0.021$) (Table 5). Symptoms measured with ASTA showed that breathlessness during activity, weakness/fatigue and tiredness were the most reported symptoms in both groups. A higher proportion of previously diagnosed patients, compared with newly diagnosed patients, reported symptoms of chest pain ($p=0.027$) and weakness/fatigue ($p=0.034$) (Figure 4).

At 6 months follow-up, newly diagnosed patients, compared with previously diagnosed patients, reported lower Illness coherence (17.3 vs. 19.0, $p=0.043$), higher personal control (19.9 vs. 17.4, $p<0.001$), AF as less cyclical (10.9 vs. 12.6, $p=0.006$), and a lower symptom burden (21.7 vs. 30.6, $p=0.004$), indicating that the newly diagnosed patients had a lower understanding of AF but greater belief in their ability to control AF. Moreover, they experienced AF as less recurrent and had a lower symptom burden than the previously diagnosed patients (Table 5).

Newly diagnosed patients, compared with previously diagnosed patients, reported better HRQoL within the ASTA HRQoL total scale (18.2 vs. 26.0, $p=0.015$) and physical subscale (20.5 vs. 32.8, $p=0.002$); however, at this time, they reported AF as chronic to the same extent (22.3 vs. 23.1, $p=0.190$) (Table 5). A higher proportion of previously diagnosed patients reported more symptoms of weakness/fatigue ($p=0.002$), cold sweats ($p=0.003$), chest pain ($p=0.021$) and pressure/discomfort in the chest ($p=0.005$) (Figure 5). Furthermore, a higher proportion of previously diagnosed patients reported AF/episodes of AF between baseline and 6 months follow-up, in comparison with newly diagnosed patients (82% vs. 60%, $p=0.006$) (Table 5).

Over time, within newly diagnosed patients, ASTA symptom burden (26.1 vs. 21.7, $p=0.001$) and anxiety symptoms (HADS-A) decreased (4.7 vs. 3.8, $p=0.014$). HRQoL improved within the ASTA total scale (24.1 vs. 18.2, $p=0.002$), the physical subscale (28.1 vs. 20.5, $p=0.001$) and the mental subscale (19.2 vs. 15.5, $p=0.014$). However, their belief in treatment control decreased (18.6 vs. 17.7, $p=0.035$), and they now reported AF as chronic to a greater extent than at baseline (19.5 vs. 22.3, $p<0.001$). In previously diagnosed patients, there were no changes in PROs over time (Table 5).

Table 5. Differences between and within groups of patients newly diagnosed (<6 months) and patients previously diagnosed with atrial fibrillation (≥6 months) in patient-reported outcome measures

Scales (score range)	Between groups at baseline			Between groups at 6 months			Differences within groups	
	Newly	Previously		Newly	Previously		Newly	Previously
ASTA, mean (SD)			p^a			p^a	p^c	p^c
Symptoms (0–100)	26.1 (15.1)	31.9 (15.4)	0.065	21.7 (16.1)	30.6 (17.2)	0.004	0.001	0.708
HRQoL total (0–100)	24.1 (17.1)	27.6 (17.7)	0.386	18.2 (16.7)	26.0 (20.2)	0.015	0.002	0.791
HRQoL physical (0–100)	28.1 (21.2)	32.4 (22.4)	0.424	20.5 (20.3)	32.8 (25.2)	0.002	0.001	0.480
HRQoL mental (0–100)	19.2 (15.6)	22.0 (16.5)	0.427	15.5 (15.0)	19.4 (18.7)	0.304	0.014	0.111
HADS, mean (SD)								
Anxiety (0–21)	4.7 (3.4)	3.8 (2.9)	0.093	3.8 (3.5)	3.6 (3.2)	0.929	0.014	0.633
Depression (0–21)	3.0 (2.8)	3.0 (2.7)	0.986	2.8 (2.6)	2.8 (2.6)	0.935	0.310	0.146
HADS, ≥8, %								
Anxiety	25.0	9.6	0.021^b	17.0	9.6	0.219 ^b	0.289 ^d	1.000 ^d
Depression	7.5	8.1	1.000 ^b	3.8	2.7	1.000 ^b	0.625 ^d	0.219 ^d
IPQ-R, mean (SD)								
Timeline acute/chronic (6–30)	19.5 (4.6)	22.4 (5.0)	0.003	22.3 (4.5)	23.1 (5.5)	0.190	<0.001	0.156
Consequences (6–30)	15.7 (3.6)	17.1 (4.7)	0.101	16.0 (3.8)	17.0 (4.6)	0.093	0.663	0.731
Personal control (6–30)	19.7 (3.1)	17.9 (3.8)	0.004	19.9 (3.2)	17.4 (4.2)	<0.001	0.855	0.174
Treatment control (5–25)	18.6 (2.3)	17.6 (2.9)	0.041	17.7 (2.7)	17.1 (3.3)	0.213	0.035	0.220
Illness coherence (5–25)	17.4 (3.5)	17.9 (4.3)	0.422	17.3 (4.3)	19.0 (4.1)	0.043	0.627	0.159
Emotional representations (6–30)	15.9 (4.5)	15.0 (4.2)	0.283	15.3 (4.1)	15.0 (4.6)	0.890	0.203	0.852
Timeline cyclical (4–20)	11.2 (3.2)	12.6 (3.1)	0.019	10.9 (3.7)	12.6 (2.9)	0.006	0.634	0.460
AF/episodes of AF Yes %				59.6	81.6	0.006^b		

Bold numbers denote statistically significant *p*-values. ^aMann-Whitney U test, ^bChi-square test, ^cWilcoxon's signed rank test, ^dMcNemar's test

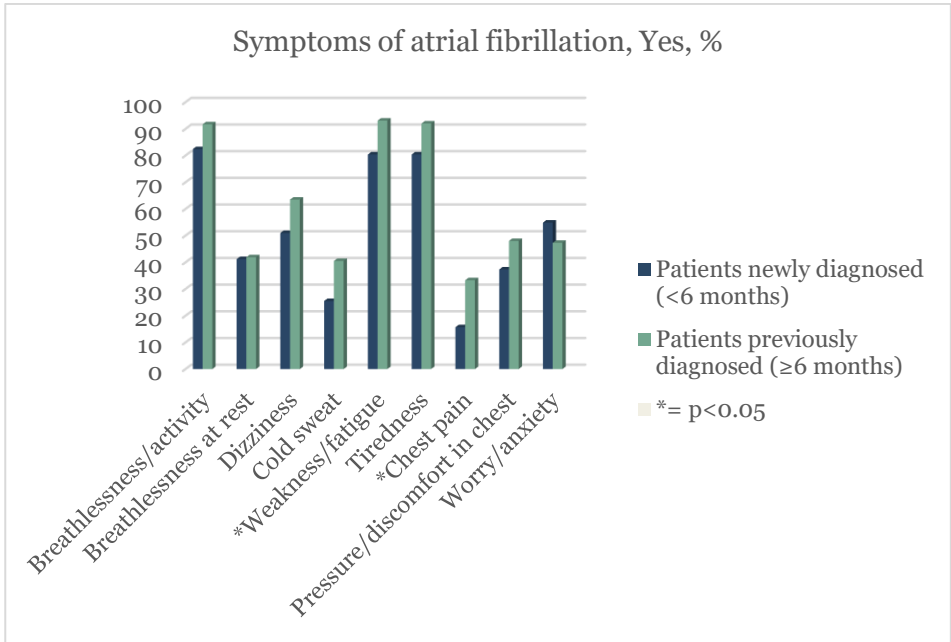


Figure 4. Differences in symptoms between patients newly diagnosed and those previously diagnosed with AF at baseline

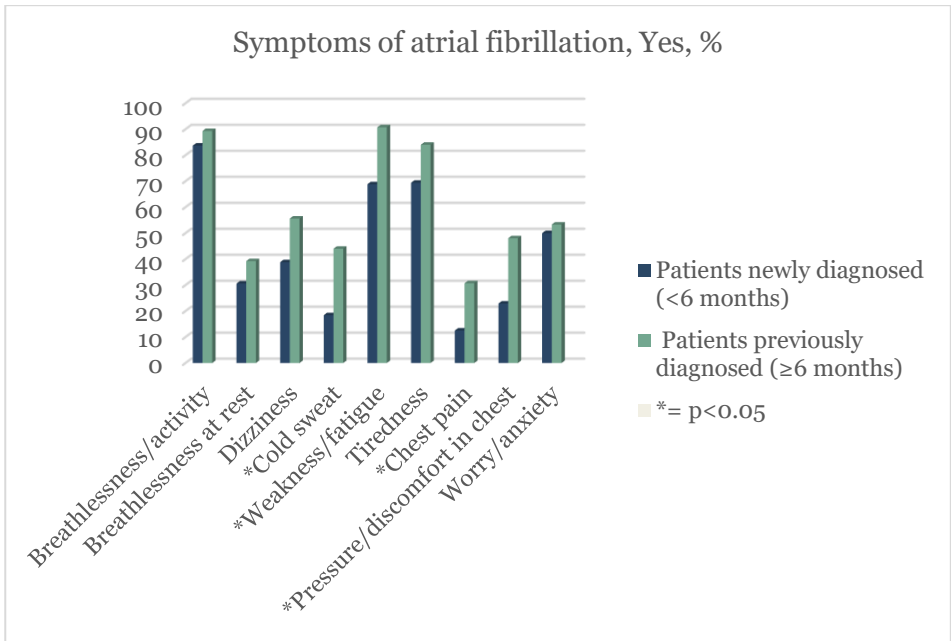


Figure 5. Differences in symptoms between patients newly diagnosed and those previously diagnosed with AF at 6 months

Evaluation of a nurse-led person-centred clinic in AF

Health-Related Quality of Life

There were no differences between the two groups in HRQoL, either at baseline or at 6 months. However, within both groups, HRQoL improved over time in the mental subscale of ASTA, indicating that the patients experienced, for example, less worry and sadness because of AF over time (intervention group: 22.6 vs. 18.0, $p=0.017$; control group: 19.0 vs. 15.8, $p=0.039$) (Table 6).

Table 6. Differences in HRQoL and symptom burden between and within groups over time

Scales (score range) [n=intervention/control]	Baseline [n=50/53] Mean (SD)	6 months [n=47/42] Mean (SD)	p^1	p^2	p^3	p^4
ASTA						
HRQoL total (0–100)			0.690	0.914	0.658	
Intervention	23.1 (20.2)	19.4 (18.9)				0.067
Control	20.2 (15.6)	18.3 (16.0)				0.202
HRQoL physical (0–100)			0.888	0.541	0.594	
Intervention	23.5 (24.6)	20.7 (22.8)				0.170
Control	21.1 (18.8)	20.3 (17.8)				0.808
HRQoL mental (0–100)			0.464	0.697	0.968	
Intervention	22.6 (18.8)	18.0 (18.3)				0.017
Control	19.0 (15.6)	15.8 (16.8)				0.039
Symptoms (0–100)			0.979	0.804	0.215	
Intervention	26.0 (18.4)	25.2 (18.0)				0.336
Control	24.9 (16.3)	25.3 (17.7)				0.454
EuroQol-5D						
Index (0–1)			0.805	0.777	0.806	
Intervention	0.72 (0.25)	0.76 (0.26)				0.100
Control	0.68 (0.25)	0.76 (0.25)				0.091
EuroQol-VAS						
VAS (0–100)			0.319	0.966	0.136	
Intervention	67.4 (18.1)	70.1 (17.6)				0.416
Control	70.7 (17.0)	69.9 (17.6)				0.120

Bold figures denote statistically significant p-values. p^1 =Differences between groups at baseline; p^2 =Differences between groups at 6-months; p^3 =Differences between groups over time; p^4 =Differences within-groups over time

Symptom burden

The patients in both groups showed no improvement in symptom burden (ASTA) over time, between groups or within groups (Table 6).

Symptoms of anxiety & depression

Despite the randomisation, the participants in the intervention group reported higher mean scores in HADS-A than the control group at baseline (5.6 vs. 3.9, $p=0.044$), indicating a higher degree of anxiety symptoms. However, at 6 months, there were no differences between the two groups. A higher proportion of participants in the intervention group scored ≥ 8 at baseline, in both HADS-A and HADS-D than the control group did (34.0 % vs. 9.4 %, $p=0.002$, and 16.0 % vs. 1.9 %, $p=0.014$ respectively) (Table 7). This indicates that more participants in the intervention group had symptoms of anxiety and depression than those in the control group.

Illness perceptions

At baseline, the two groups were comparable in all subscales of illness perception. However, over time, the participants in the intervention group reported decreased emotional representation compared with those in the control group (Mean difference, -1.0, $p=0.014$). This meant that feelings such as anxiety, worry and anger because of AF decreased more in the intervention group compared to the control group (Table 7).

Furthermore, over time, within the intervention group, the participants reported higher levels of illness coherence (5.2 vs. 7.1, $p<0.001$) and improved personal control (3.8 vs. 5.2, $p<0.014$), and their emotions and concerns that were attributed to AF decreased (4.2 vs. 3.1, $p<0.001$ and 5.2 vs. 4.2, $p=0.011$, respectively). This result suggests that their understanding of AF and their belief in themselves being able to control the AF improved, while their worries and concerns regarding AF decreased. In the control group, illness coherence improved over time (5.5 vs. 6.7, $p=0.042$) (Table 7).

Table 7. Differences in anxiety- and depression symptoms and illness perceptions between and within groups over time

Scales (score range) [n=intervention/control]	Baseline [n=50/53]	6 months [n=47/42]	p^1	p^2	p^3	p^4
HADS, mean (SD)						
Anxiety (0–21)			0.044	0.183	0.303	
Intervention	5.6 (4.3)	5.0 (4.2)				0.248
Control	3.9 (3.4)	3.6 (2.9)				0.696
Depression (0–21)			0.150	0.970	0.082	
Intervention	4.1 (3.2)	3.6 (2.9)				0.332
Control	3.1 (2.5)	3.5 (2.7)				0.091
HADS ≥8, %						
Anxiety			0.002	<0.001		
Intervention	34.0	38.3				0.727
Control	9.4	7.1				1.000
Depression			0.014	0.742		
Intervention	16.0	13.0				1.000
Control	1.9	9.5				0.125
B-IPQ, mean (SD)						
Consequences (0–10)			0.427	0.552	0.679	
Intervention	4.0 (2.7)	3.8 (2.8)				0.371
Control	3.7 (2.4)	3.4 (2.4)				0.534
Timeline (0–10)			0.820	0.288	0.122	
Intervention	7.2 (2.8)	7.0 (3.3)				0.818
Control	7.0 (2.8)	7.8 (3.0)				0.065
Personal control (0–10)			0.638	0.520	0.548	
Intervention	3.8 (2.9)	5.2 (3.2)				0.014
Control	3.5 (3.1)	4.7 (3.0)				0.140
Treatment control (0–10)			0.807	0.943	0.563	
Intervention	7.4 (2.2)	7.2 (2.2)				0.652
Control	7.4 (2.2)	7.1 (2.6)				0.262
Illness identity (0–10)			0.819	0.483	0.664	
Intervention	3.8 (2.8)	3.5 (2.3)				0.647
Control	3.5 (2.2)	3.1 (2.3)				0.940
Concern (0–10)			0.138	0.473	0.218	
Intervention	5.2 (3.0)	4.2 (2.9)				0.011
Control	4.3 (2.7)	3.9 (2.8)				0.472
Illness coherence (0–10)			0.677	0.571	0.137	
Intervention	5.2 (3.0)	7.1 (2.7)				<0.001
Control	5.5 (3.1)	6.7 (2.9)				0.042
Emotional repr. (0–10)			0.231	0.709	0.014	
Intervention	4.2(3.0)	3.1 (2.6)				<0.001
Control	3.5 (2.8)	3.4 (3.0)				0.899

Bold figures denote statistically significant p-values. p^1 =Differences between groups at baseline; p^2 =Differences between groups at 6 months; p^3 =Differences between groups over time; p^4 =Differences within-groups over time

Discussion

This thesis aimed to explore experiences of AF and evaluate the effects of a nurse-led, person-centred clinic. The main findings revealed that the participants in Study I strove to comprehend and gain control over the illness and lacked someone to turn to for support. At the same time, they were grappling with a changed self-image. The participants considered that their physician appointments mainly focused on medical issues, whereas they were searching for an increased understanding and knowledge of AF by themselves. Most participants wanted to get involved in their care. There were differences in their experiences, but all experienced a transition in which they had to learn how to balance their life (Study I). Study II showed that illness perceptions affected the participants' HRQoL. More perceived symptoms, consequences and emotional representations (e.g. anger and worry) being attributed to AF and experiencing the AF as constantly recurring (cyclic) were associated with worse HRQoL. Women experienced worse HRQoL and personal control than men did (Study II). In Study III, the newly diagnosed patients reported more positive outcomes in terms of HRQoL, symptoms and symptom burden, and had a greater belief in personal control than those with an earlier diagnosis of AF. Study IV showed that support from a nurse-led, person-centred clinic decreased patients' negative emotions regarding AF in comparison with the control group. In addition, their belief in their ability to control AF increased, while their concerns decreased. In both groups, HRQoL and the understanding of AF increased.

Perceiving and managing illness

The participants described their first experience of the symptoms of AF when they discovered that something was wrong. It was noted that the described symptom experiences varied between participants, especially at onset (Study I). The most common symptoms that were reported by the newly diagnosed patients were shortness of breath during activity (82%), weakness/fatigue (80%), tiredness (80%) and worry/anxiety (50%) (Study III), which is quite a high proportion of patients having these symptoms. Similar results or an even higher proportion of symptoms were reported in a previous study; however, in that study, the participants completed the questionnaire before catheter ablation.¹³ One explanation for the high rate of reported symptoms for the newly diagnosed patients could be that the patients completed the

questionnaire prior to their planned electrical conversion and were experiencing AF at the time of measurement (Study III).

Some of the participants formulated theories about the causes of the symptoms, such as lifestyle, mental exhaustion and stress, while others who were interested in exercising thought that their symptoms were caused by too little exercise and responded by increasing it (Study I). Similar findings were reported by McCabe et al., who found that only a few patients were aware of the symptoms and significance of AF before diagnosis.¹²³ This is a huge problem, since lack of awareness may delay diagnosis and can lead to increased risk of an ischemic stroke. According to the CSM, symptoms act as key factors that initiate the process of how to cope with an illness or a health threat.⁹⁶ Furthermore, the person's experience of the symptoms and how she or he perceives them is important, since it affects how she or he acts and copes with the situation.¹²⁴ Previous experiences and social, cultural and environmental factors influence a person's perception of her or his symptoms. This perception influences the person's emotional response towards the illness and her or his coping behaviours.^{96,125} This explains why patients with the same illness perceive it, react to it and act in different ways.⁹⁶ In Study II, some patients associated symptoms such as stiff joints and red eyes with AF, even though such symptoms are not linked with AF from a medical perspective. According to the CSM, an explanation could be that patients who receive a diagnosis develop cognitive beliefs about the symptoms caused by the disease. Their beliefs depend on their past experiences and on the knowledge they possess.⁹⁶ Thus, if the person has experienced or heard that someone else has had the same symptoms, or if the symptoms arose in connection with the onset of AF, it is not strange to associate these symptoms with the condition. Healthcare professionals need to be aware that patients may associate symptoms with AF that are not typically considered AF symptoms. This illustrates the importance of early support and information about the illness.

Worse HRQoL was associated with attributing more symptoms, consequences and negative emotions to AF and experiencing AF as recurrent (Study II). Beliefs in severe consequences and a strong illness identity may lead to avoidance/denial.¹²⁴ This could explain why some people with AF delay seeking care. Taylor et al. reported results from a recent cluster analysis study that showed patterns of behavioural and cognitive reactions to symptoms from patients with AF.¹²⁶ The results showed that people who more often avoided activities due to their belief that symptoms were caused by the activities showed more distress and worse QoL compared with those who paid less attention to symptoms

and had reduced behavioural avoidance.¹²⁶ Patients with a pessimistic outlook on the consequences and their control of illness may experience greater emotional stress and reduced treatment engagement, increasing their risk of unfavourable outcomes.^{124,127} A high perceived control of the illness correlates to vitality and psychological well-being.¹²⁴ In Study III, more newly diagnosed patients reported higher personal control and better HRQoL at 6 months follow-up than those with an earlier diagnosis. This might have been because the former had not had as many recurrences of AF. However, since there may be a risk of behavioural avoidance becoming a vicious cycle of distress caused by the condition and belief in its severe consequences,¹²⁶ it is important to identify those who are most at risk. In the meeting with the patient, this can be done by asking about the perception of the illness or by using questionnaires, such as the B-IPQ. Follow-up should also be adapted to provide the support needed based on the patient's needs and preferences.

Worse HRQoL was associated with the negative emotions and consequences the patients attributed to AF (Study II). McCabe et al. found that patients with a higher perceived understanding of AF reported fewer consequences and negative emotions due to AF and experienced greater control.¹⁰⁶ A person who understands her or his illness (high illness coherence) can be more adherent to treatments.¹²⁸ Increasing patients' understanding of AF and supporting their belief in their ability to control AF can reduce negative emotional reactions and improve HRQoL.

Struggling to balance life and illness

The participants described the various ways in which they struggled to control and manage the illness to keep life as normal as possible. The problem was that the AF was recurring, which made it difficult to perform activities as desired. The consequences led them to avoid some activities in fear of a recurrent episode of AF (Study I), a finding that aligns with the results from other studies.^{1-3,129,130} McCabe et al. found that patients struggled to understand AF and predict symptoms and used different strategies to get rid of the symptoms, which usually only helped for the moment.³ Aiming to highlight patients' need for support and information, Redman et al. explored conversations on a website where people with AF shared their experiences of treating AF differently. The need for information was great, and the participants returned several times to the website to learn from each other how to manage AF, sometimes using a mixture of conventional and alternative medicine.¹³¹ According to the CSM, a person who perceives that a health threat is

uncontrollable and a source of emotional distress may adopt a denial approach and avoid dealing with the threat.¹³² This would mean that the health threat persists or returns, and the self-regulation process will start all over again. In Study III, patients who were newly diagnosed appeared to have a greater belief that they could control AF than patients that had been diagnosed earlier. However, this may be explained by the fact that newly diagnosed patients had not had a recurrence of AF and did not have to struggle to gain control to the same extent as those who had had AF longer. Furthermore, the newly diagnosed patients did not perceive AF as chronic to the same extent, which may have given them a sense of security (Study III). A chronic illness is a long-lasting, most often controllable, but not curable condition. AF is often paroxysmal initially, and a long time can pass between recurrences. Over time, however, AF often tends to increase in frequency, duration and symptoms, and becomes more persistent.⁸ One way to prevent AF recurrence and its symptoms is through lifestyle changes and risk factor management, which have been shown to reduce symptom burden and symptom severity,¹³³ as well as the progression of the disease.³⁶ In addition to being a long-term risk marker for AF,²⁸ alcohol can act as a trigger for the recurrence of AF.^{32,134} Patients also report psychic stress as a triggering factor.³² Therefore, in addition to working against risk factors through an improved lifestyle, it is important to understand what can trigger and prevent an episode of AF. RNs play a vital role in motivating patients and providing support to help patients cope with this. RNs often have more time and greater opportunity to emphasise these areas than physicians, who often have a shorter time for visits, with a significant portion of that time being dedicated to the purely medical aspects of care.

Dealing with a changed self-image

The participants described how their perception of themselves changed and how they had difficulty defining themselves when AF was so unpredictable. The abrupt changes between feeling strong and normal one moment and weak the next affected their daily life in many ways. Almost everyone described having some problem with this, but those who had usually perceived themselves as strong had a harder time accepting the changes that AF entailed (Study I). An exploration of altered self-image in AF has not been found in the literature. In a review, Wang et al. found that changes in patients' roles or identities reduced their self-worth.¹³⁰ Charmaz¹³⁵ explored the concepts of self, self-concept, self-image and identity as analytical tools that can help in understanding how, why and when people change or develop. Illness can compel people

to alter the way they view themselves. These changes can appear as minor adjustments in daily routines and habits or as profound changes that reshape people's existence.¹³⁵ In a qualitative study of severe chronic illnesses, the participants described experiences of physical, emotional and social loss. Loss of identity, including self-image, was included and could lead to chronic sorrow.¹³⁶ The Shifting Perspectives Model of Chronic Illness characterises living with chronic illness as an ever-evolving, dynamic process. It recognises that individuals continually shift between wellness and illness perspectives, allowing them to make sense of their illness experiences. Sometimes, the disease is in the foreground, causing individuals to focus on symptoms and limitations due to the disease. However, when well-being is in the foreground, individuals can transcend illness and focus on aspects of their identity beyond their health.¹³⁷ However, AF may differ from other chronic illnesses in this sense, since it is often unpredictable and may occur several times per day, with unpleasant and threatening symptoms. It is important for healthcare professionals to be aware that patients may have a changed self-image due to AF and to address this during appointments by asking patients about their view of AF and themselves and their experience of how the condition has affected them.

Integrating illness into daily life

Time seems to be an important factor in people's well-being and experience of AF. Newly diagnosed patients rated worse HRQoL, higher symptom burden and more symptoms of anxiety at the beginning than they did after 6 months. However, something seemed to change after that; for patients with a longer diagnosis, there was no change over time in symptom burden, HRQoL or any other patient-reported outcome, other than an improved understanding of AF (Study III). Hagger et al. used the CSM to explain that a person's perception and emotions towards the disease and its impact on coping strategies are expected to differ depending on whether the diagnosis is recent or more distant, with long experience of the condition. At first, the threat is new and can be frightening and unsettling. As time passes, and the person gains more information and experience with symptoms and treatment, the effect shifts towards an increased use of problem-focused coping strategies.¹³² In Study I, patients learned over time to manage both anxiety and symptoms. However, one explanation for the results in Study III may be that it is a progressive condition, and symptoms often increase in frequency and severity, with a possibly worse HRQoL. Another explanation could be that, over time, the participants more or less had to accept their life changes, which aligns with findings from previous

studies.^{2,130} Accepting the condition has been shown to improve HRQoL.¹³⁸ However, some people with AF seem to have difficulty fully accepting the condition because they never seem to give up the search for a new treatment or a chance for a cure.³ Perhaps this is why the patients with a previous diagnosis of AF did not report any improvement in HRQoL over time in study III. Getting patients to integrate the illness is not easy, especially if they are constantly looking for a cure. In this thesis, I use the term ‘integrate’ to refer to how people adapt over time to reach a balance between managing AF and living a meaningful life.¹³⁹ In their study of people with type II diabetes, Hörnsten et al. found that there is a turning point at which individuals begin to integrate their illness emotionally and existentially. The participants’ experiences with a serious illness acted as a catalyst, speeding up their integration of illness and self-management.¹⁴⁰ Research on illness integration in people with AF has not been found. However, the results described above may indicate that nurses caring for AF patients should be aware of illness integration. More studies are needed in this area, mainly as people’s experiences of AF differ greatly.

Needing support and to be involved

Participants in Study I expressed a desire to be involved in their care and decision-making, although some preferred not to be. Wang et al. observed the same attitudes in their review.¹³⁰ Even if the patient is not actively involved in decision-making, supportive and affirming communication can make the person feel involved.¹⁴¹ Since experiences of AF differed between patients (Study I), a finding that has also been reported in other studies,^{2,3,31,123,142} the conclusions in Study I proposed the use of PCC in the management of patients with AF. In addition to individualised care, PCC may give people with AF a better opportunity to be actively involved in their care, based on their values and preferences.^{57,66,67} Some healthcare professionals mistakenly believe that inviting patients into decision-making means allowing patients to decide their own treatment, which is not the actual goal. However, patients should be informed of the available options and allowed to participate in decision-making based on feasibility. Allowing patients to participate in their care may strengthen their self-esteem and belief in their abilities.

The patients in Study I reported that they wanted someone to talk to and turn to for support, in regard to both medical issues and their worries about coping with the illness – a finding that aligns with previous studies.^{3,130} Previous research has shown that patients do not always get the kind of support they need and want,^{3,56,131} and that their healthcare

visits often have a medical focus that the patients find difficult to understand.⁵⁶ Patients want and need more knowledge,^{143,144} as well as support in preventing and managing AF. A review showed that patients need reassuring information and support to reduce the stress and anxiety they feel, if possible; in turn, this can make it easier to develop strategies to manage the disease while simultaneously increasing their QoL.¹³⁰ This finding aligns with the CSM, which indicates that negative emotional reactions such as anger, anxiety and worry about a health threat negatively can affect the person's ability to cope with the illness.¹²⁵ Studies I–III all concluded that patients with AF needed support and more knowledge about AF. Study II also concluded that, in addition to giving patients information, patients should be given space to talk about their emotions, consequences and experiences of AF.

Patients' knowledge of AF has been shown to be insufficient.¹⁴⁵ Despite being instructed, informed and educated, they may have problems understanding the information given, especially if it is medically oriented,^{56,130} which was shown to be a problem for some of the participants in Study I. Therefore, we cannot presume that all patients comprehend the effects of risk factors in general and on the development and deterioration of AF. Furthermore, our results showed that women, in comparison with men (Study II), and previously compared with newly diagnosed patients with AF (Study III), had less faith in their ability to control AF (personal control), which should be taken into consideration when supporting and educating patients. Lane et al. highlighted the significance of providing patients with personalised education.¹⁴⁶ That is, information should be given that is at the person's level, supplemented with easy-to-read written information and recommendations about readable and reliable websites with accurate information.

Improving self-care and emotional adaptation

Some studies on nurse-led care compared with usual care in AF have shown beneficial effects of the former on outcomes, such as hospitalisation, death,^{53,54} cost-effectiveness,⁵⁴ HRQoL,^{51,54} depression and anxiety,⁵¹ while others have not.⁵⁵ When evaluating the nurse-led clinic (Study IV), we hypothesised that support from the nurses would lead to improved HRQoL and illness perception and reduced symptom burden, anxiety and depression over time, both within the group and in comparison with the control group. The results of Study IV showed that, over time, patients within both groups better understood AF (illness coherence), and their mental HRQoL improved. Moreover, compared with the control group, patients' emotional responses towards AF in the

intervention group decreased significantly. The reason for this might be that RNs do not only focus on medical aspects but may also provide more comprehensive care. When visiting a physician, patients may occupy a relatively subordinate position in the doctor-patient relationship and might need more support to bridge the information gap.¹³⁰ The RNs in Study IV had been trained in PCC, and the patient's narratives and the questionnaire about illness perception¹⁰⁰ formed the basis of the conversation, which may have contributed to the focus being placed on the parts that were beneficial to the patient. PCC considers the perspectives of both patients and professionals, emphasising not only an understanding of the disease but also the personal capabilities and goals of patients.¹⁴⁷ A study involving patients with acute coronary syndrome found that, when patients identified their own goals and resources, these often encompassed maintaining social relationships and regaining the ability to participate in significant activities, such as work. Their narratives highlighted both their strengths and the areas where they required support.¹⁴⁷ The patients' visits to the nurses lasted slightly longer than those to the physicians, and most patients in the intervention group had a follow-up phone call regarding their condition and the goals (health plan) they set together with the nurse. This may have been experienced as a form of security by the patients. The patients in Study I also described that they wanted someone to have contact with and to know where to turn to with questions (Study I). Thus, the security of having a contact who is easy to reach may have contributed to the findings. Most of the physicians in the control group were undergoing education and only worked for a period of time at the clinic. It is possible that, because the patients in the intervention group were given space to talk about themselves and their illness, they were able to express their emotions and the consequences they experienced as a result of AF, which reduced their negative emotions and concerns.

In addition to gaining a better understanding of AF, the within-group analysis showed that patients' belief in their ability to control AF improved over time in the intervention group. According to the CSM, individuals who make sense of their illness (high illness coherence) will have a greater belief in their control over their illness.¹²⁸ However, in the control group, even if the patients reported an increased understanding of AF, their belief in their personal control did not significantly improve. One explanation for improved personal control in the intervention group may be that patients' emotions and concerns decreased. Reduced emotional distress in response to a health threat often leads to an increase in the patient's ability to cope with the condition.¹²⁵ Supporting patients in gaining a better understanding of AF and strengthening their

self-care skills can increase their ability to manage AF and its risk factors and thereby counteract the development of the disease. This can lead to a reduced burden of symptoms, such that patients can dare to carry out their daily activities and thereby further improve their HRQoL. Nevertheless, more research is needed in this area.

Methodological discussion

Various methods were used to answer the research questions of this thesis. Using both qualitative and quantitative methods provides a more comprehensive understanding of the phenomenon under study by viewing it from different perspectives.¹⁴⁸ In addition to quantitative methods such as questionnaires, the interviews provided a more comprehensive and detailed account of people's experiences of living with AF. However, as discussed by Sandelowski,¹⁴⁹ despite their apparent differences, both the questionnaire and the interview responses are ultimately treated as surrogates for the complexity of a person's experiences.¹⁴⁹ Some methodological considerations will be discussed below.

Conducting clinical studies during a pandemic was challenging and created many issues. The recruitment of participants for Studies II and III had to be interrupted when the COVID-19 pandemic broke out, and the restrictions on researchers visiting the hospital worsened. The pandemic created the most problems for Study IV. The evaluation of the nurse-led clinic began in late October 2020, when the pandemic was originally expected to be over. Due to a resurgence of the pandemic, patient recruitment was affected; several people refused to participate because they did not want to visit the hospital. Many visits were also changed to telephone calls. Evaluating the effects of a person-centred nurse-led outpatient clinic on outcomes such as HRQoL, anxiety and depression in patients in the middle of a pandemic may have affected the results, as many people's levels of anxiety and depression may have been exacerbated by the pandemic.¹⁵⁰ As we did not achieve the required number of participants for Study IV and, therefore, did not reach the desired statistical power, conclusions from that study should be drawn with caution.

External validity pertains to the sample generalisability – that is, the extent to which the results obtained from a specific study sample can be confidently applied to the larger population from which the sample was selected. It assesses the feasibility of extending study findings to diverse

populations or different settings.¹⁵¹ All studies were conducted as single-centre studies which limit its generalizability; however, the study populations in all studies are well described. In study II and III, we did not have such strict criteria for inclusion, which meant we had a real-world population of patients with AF, scheduled for an electrical conversion, which must be considered a strength. In study IV however, rather, narrow criteria were set, such as the participants should not having severe heart failure or be waiting for heart surgery or ablation. This was performed to reduce the risk of other factors negatively impacting HRQoL. The effect of this was that the participants estimated HRQoL almost as well as the average Swedish population, which makes it a bit difficult to observe changes in HRQoL, at least for the generic instruments EQ5D and EQ-VAS.

Interviews and quality content analysis

Study I was a qualitative study with interviews of people living with symptomatic AF. In qualitative research, trustworthiness is essential and is often described with concepts such as credibility, dependability and transferability.^{118,152} Credibility requires thorough consideration and execution of the method, sample, data, setting and analysis. The participating patients were selected from among those who had described symptoms associated with AF at the time of inclusion in the questionnaire studies (Studies II and III). To gain a broad range of experiences, a purposive selection was made in terms of age, gender and years living with AF, which strengthens the credibility and transferability of the findings.¹¹⁹ The participants could choose whether to be interviewed in their homes or at the hospital. Four RNs conducted the interviews, none of which were involved in the participants' care. Two were RNs with PhD degrees, experience in interviewing, and experience in the illness under study, while the other two were RNs undergoing specialist training. Having multiple interviewers can be both disadvantageous and advantageous. In this case, two of the interviewers were relatively unfamiliar with AF, which could have caused them to ask more follow-up questions about things they did not understand, resulting in a deeper understanding of the interviewees' experiences. The two interviewers who were more familiar with AF and had worked in this area for a long time may have interpreted the interviews based on their own experience and thus missed chances to ask follow-up questions. On the other hand, the two interviewers with more experience with patients with AF also had more interviewing experience and thus knew what follow-up questions to ask. To achieve dependability, the interviews were conducted using a semi-structured interview guide, and the same

question areas were focused on in all the interviews. Probing questions were used to gain a deeper understanding of the patients' experiences of living with symptomatic AF.¹⁰⁸

With the intention to describe, interpret and achieve trustworthiness, qualitative content analysis based on the work of Graneheim et al. was used.¹¹⁸⁻¹²⁰ This analysis method was well suited to the purpose, which was to explore people's experiences. To promote transferability, we followed and described each step throughout the data collection and the analysis process. Representative quotes were included in the presentation of the results to achieve credibility. Regarding the dependability of the results, there is always a risk of researchers bringing their own feelings and experiences into the analysis. Therefore, the authors conducting the analysis reflected on and discussed their interpretations at each step until consensus was reached. Nevertheless, the decision regarding the applicability of this study to other contexts ultimately rests with the reader.¹⁴⁸

Questionnaires and quantitative studies

The advantage of questionnaires is that they are a relatively simple method that can generate responses from many people, and many different surveys can be included in the same questionnaire. In Studies II, III and IV, we used commonly used and validated questionnaires.^{99,100,109-112} Validity refers to the accuracy of a measure. To obtain more comprehensive results, we employed generic, disease-specific, and domain-specific questionnaires. Furthermore, the high Cronbach's α values that were obtained may increase the reliability of the results, since a Cronbach's α value of 0.70 or greater indicates good reliability.¹⁵³ Only a few items had a Cronbach's α value just below 0.70 (in Studies II and III).

The disadvantages of using questionnaires are that some people either do not return them at all ('lost to follow-up') or only partially answer them ('missing items'). The question then becomes what to do with missing items. Even if some items can be imputed, some will be handled as missing. However, the suitability of imputing missing data should be reflected upon, considering that substituting information could raise concerns about the study's validity. In the cases where we imputed data, we followed the advice of the respective instrument developers regarding imputation (ASTA and IPQ-R). Missing items in the scales within ASTA and IPQ-R were replaced with the sum score mean value for the individual.¹²¹ For the HADS, we did not find any advice regarding

imputation from the developers. According to Bell et al., a half-rule is recommended for imputing the individual subscales in the HADS, which means that up to half of the items can be replaced at the individual level.¹⁵⁴ We only replaced if one item out of seven was missing in each HADS scale. This approach boosts statistical power by incorporating data from participants who would have otherwise been excluded. Furthermore, since inserting an individual's mean value does not change the total variance, the mean of each sum score remains unaffected. Therefore, imputing missing data appears to be a viable strategy and should be considered.

Study II relies on cross-sectional data collected at a specific point in time. This research design offers several advantages, such as the ability to explore multiple explanatory variables simultaneously in large samples at relatively low cost.¹⁵⁵ The study participants (Study II) had a wide spread of ages (22–86 years), differences in time diagnosed with AF (0–400 months) and different types of AF (paroxysmal and persistent) and included both women and men. However, this design also has its limitations. Cross-sectional studies pose challenges in establishing cause-and-effect relationships.¹⁵⁵ Although potential causes are discussed, these should be viewed as ideas for generating hypotheses in future studies. These studies simultaneously collect data from various individuals, providing a snapshot of the population's characteristics during that specific moment. However, due to their limited scope, cross-sectional designs cannot definitively determine causality. Instead, they offer valuable insights into associations and correlations between variables.¹⁵⁵

A longitudinal study (Study III) repeatedly examines the same individuals over a period of time, which provides a deeper understanding and allows valuable insights into cause-and-effect relationships.¹⁵⁶ Study III followed the same people as Study II over a 6-month period. At 6 months, the response rate was 75%, which is quite a high rate. However, the number of participants was relatively low, at 129; moreover, in determining group differences between newly and previously diagnosed patients, the groups were even smaller, at 53 versus 76. This may have caused a type II error (failure to detect an existing difference). Another disadvantage of this type of study is that the follow-up of participants can be incomplete and interrupted, resulting in a loss of follow-up over time.¹⁵⁶

Randomised controlled studies are widely regarded as the 'gold standard' in research, especially when double blinded. While individual

studies are unlikely to definitively establish causality, randomisation helps to mitigate bias and offers a robust approach for investigating cause-and-effect relationships between interventions and outcomes.¹⁵⁷

One strength of Study IV is that it followed the CONSORT guidelines.¹⁵⁸ In addition, the study was registered at clinicaltrials.gov. Furthermore, randomisation minimises the risk of bias, even though chance may lead to uneven group distribution. That was the case in this study, since a higher proportion of the intervention group had symptoms of anxiety and depression at baseline, compared with the control group. When dealing with a smaller study, we opted for a block randomisation of ten, to minimise the risk of skewed group sizes. To minimise the risk of selection bias, randomisation was performed with the help of people outside the research group. The results were then analysed without knowledge of group affiliation, allowing them to be objectively reviewed. A risk in randomised controlled studies is the loss of follow-up, which can cause a nonresponse bias that can undermine the findings' reliability and validity.¹⁵⁹ We performed a dropout analysis of the non-responders and compared them with the completers of the questionnaires at the six-month follow-up. The non-responders were younger (60 vs. 69 years), and more were still working (50% vs. 33%); moreover, they reported worse HRQoL as measured by the EQ-VAS at baseline (58 vs 71) compared to the completers. There is a risk that this might have affected the results of the study. However, we had a response rate of 86% at 6 months, which is high. A high response rate can minimise the problem of nonresponse bias.¹⁵⁹

Conclusions

The overall aim of this thesis was to explore patients' experiences of AF and to evaluate the effects of a nurse-led, person-centred clinic.

Living with AF differs between people; however, for most, it means a change in life. Having AF can mean having to manage anxiety and symptoms and oscillate between feeling strong and weak, accepting changes, and becoming dependent on care and a changed self-image. Illness perceptions, such as linking more symptoms and severe consequences to AF and experiencing AF as recurrent, can negatively affect HRQoL, as can the negative emotions towards the disease that occur. This can reduce the person's ability to manage AF. How the patient is affected during the illness trajectory can differ. However, newly diagnosed patients reported better outcomes, such as greater confidence in personal control in AF and higher HRQoL, than those with an earlier diagnosis. Support from a nurse-led, person-centred clinic was found to decrease negative emotions towards AF to a greater extent than a physician's appointment; in addition, patients' concerns associated with AF decreased, and their confidence in their ability to control AF improved.

Clinical implications and future research

- Healthcare professionals should be aware that patients' views of symptoms that belong to AF may differ from symptoms that are medically agreed upon as belonging to the disease.
- The connection between illness perceptions and HRQoL suggests that efforts to alter negative perceptions can enhance HRQoL.
- Supporting patients by allowing them to talk about their symptoms and consequences and their emotions about AF can contribute to reduced anxiety and strengthen their ability to manage the disease.
- Educating healthcare professionals about illness perception and its impact and consequences can increase professionals' awareness that patients experience and manage AF differently.
- Asking patients about their perception of AF is important because it can increase healthcare professionals' understanding of how patients view their illness and ability to manage it. This

could lead to more tailored care and ultimately improved HRQoL for patients.

- The use of PROMs in patient care can facilitate more person-centred care.
- Women and patients with a longer diagnosis of AF may have lower HRQoL and belief in their ability to control the illness than men and those more newly diagnosed with AF. An individual assessment should always be made because there may be great differences among those affected by AF.

Despite the many new insights revealed in this thesis, the experiences of patients with AF are still relatively unexplored. During the work on this thesis, several new research questions emerged. In Study I, it became apparent that the patients' self-image changed over time. No studies in AF evaluating this aspect have been found, making it an area that requires more attention. Another question is whether all patients learn to accept the illness. For example, is there a turning point at which they finally integrate the illness? And, if so, does it have any significance for how they act and feel afterwards? The results in Study IV showed that negative emotions towards AF decreased more in the participants in the nurse-led group than in the control group, and the former's belief in controlling AF improved over time. An extended multicentre study including more patients is warranted. In addition, it would be interesting to evaluate the nurse-led clinic's effect on lifestyle habits and whether it has any significance for HRQoL and symptom burden. It would also be interesting to explore how the patients experienced their visits at the nurses-led clinic and whether they felt involved in their care. Since the population with AF is steadily increasing and consumes a great deal of resources, an economic evaluation of the nurse-led clinic would be of importance.

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