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Exploring the context, complexity, and magnitude of the patient perspective

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LIVING WITH ATRIAL FIBRILLATION

EXPLORING THE CONTEXT, COMPLEXITY, AND
MAGNITUDE OF THE PATIENT PERSPECTIVE

BY
VIBEKE HØGH

DISSERTATION SUBMITTED 2016



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CV

I graduated as a bachelor in nursing in 2003. My clinical nursing background is in cardiac nursing. In 2009, I received a master's degree in clinical nursing at Aarhus University and subsequently completed a research year in medical science in 2010. In 2011, I was enrolled as a PhD student at Aarhus University, and I transferred to Aalborg University in 2013.

Since my first employment as a nurse at a department of cardiology in 2003, I have always had an interest in patients living with atrial fibrillation. I experienced that these patients were being neglected, when admitted to an acute cardiac bed unit. From participating in international conferences and performing local research projects, I discovered that this tendency is an international issue. In 2010, I therefore contributed to the initiative of establishing the Danish Special Interest Group on Atrial Fibrillation for nurses, as an important step to expand the knowledge related to patients living with atrial fibrillation in Denmark.

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This PhD study was carried out during my employment in Aalborg Atrial Fibrillation Study Group, Department of Cardiology, Aalborg University Hospital.

My work would not have been possible without the outstanding support from a number of people. I want to acknowledge ‘Peter’ and his family for giving me access to their perspective of his patient journey. Great thanks to the participants in the Diet, Cancer and Health Study.

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Vibeke Høgh

ENGLISH SUMMARY

The patient perspective of living with atrial fibrillation is important for the quality of care, because the patient is the only one who experiences the events in their journey as a whole. The patient perspective is, however, complex.

Atrial fibrillation is a serious health burden, considered an epidemic, and is associated with a variety of comorbidities and an increased risk of mortality. Patients with atrial fibrillation experience being neglected and left alone with doubts and questions related to the disease, although, in clinical practice they are often being considered as the non-complex (easy) patients.

The aim of this dissertation is to explore the complexity and magnitude of the context of the patient perspective of living in the journey with atrial fibrillation.

Using a case study design, this dissertation is based on three papers, with the following results.

Based on text analysis of 53 scientific research papers the concept of quality of life is seen aligned and reduced into assessable parameters in Paper 1. This may be a sign of an implicit societal agreement within the scientific research context, and a potential threat to valuable knowledge about the patient's unique perspective. The importance of challenging definitions of, and arguments in methods applied for evaluating the concept of quality of life in a scientific context, is thereby emphasised.

Paper 2 demonstrates clinically relevant lower physical components of health status in participants from the Danish Diet, Cancer and Health study diagnosed with atrial fibrillation and/or atrial flutter compared with the remaining participants in the cohort. The results are based on generic standardised questionnaires on a population based level. Therefore, the results need to be related to the individual patient's situation in order to be applied in clinical practice.

Paper 3 demonstrates how balancing responsibility, navigating the system, adjusting to the situation, and recognition of bodily reactions are essential for the lived experience of being recently diagnosed with atrial fibrillation, and how lived experience is associated with self-reported health status assessed by both disease-specific and generic standardised questionnaires on the individual level.

In conclusion:

A person-centred and holistic perspective on the patient journey is required for providing patients living with atrial fibrillation with the needed individualised care and treatment across organisational sector boundaries.

The person-centred and holistic view is important in order to respect patients shifting perspective between illness and wellbeing when living with a chronic condition, essential for upholding the patient's dignity, balancing responsibility and strengthening the patient's autonomy.

The journey needs to be considered as an ongoing process of transition.

This dissertation contributes to the insight into how the synergy of combining both qualitative and quantitative data sources, can elaborate on the full story on the patient perspective. This knowledge is essential across organisational sector boundaries for healthcare professional and researchers engaged in caring for patients living with atrial fibrillation, and other chronic conditions.

DANSK RESUME

Patientperspektivet af at leve med atrieflimren er betydningsfuldt for kvaliteten af pleje og behandling, fordi patienterne er de eneste, der oplever deres forløb i en helhed. Patienternes perspektiv er dog komplekst.

Atrieflimren er en alvorlig kronisk lidelse og betragtes som en epidemi. Atrieflimren er forbundet med flere komorbide tilstande og med øget risiko for død. Patienter, der har atrieflimren, oplever at blive overset og ladet alene med tvivl og spørgsmål i relation til livet med sygdommen, og er ofte blevet anset som de 'nemme' patienter.

Formålet med denne afhandling er at udforske kompleksitet og mangefold af konteksten relateret til patientperspektivet i forløbet og livet med atrieflimren.

Afhandlingen er designet som et casestudie, og er baseret på tre artikler med følgende resultater:

Artikel 1 viser tegn på en social implicit hjemmel, om at begrebet livskvalitet kan reduceres til et målbart, standardiseret parameter, og sidestilles med helbredsstatus. Hvis livskvalitet udelukkende betragtes som noget, der kan måles ved hjælp af et standardiseret spørgeskema, risikerer man at overse værdifuld individuel information om patientens situation som en helhed. Dette konkluderes på baggrund af en tekstanalyse af 53 videnskabelige artikler, der omhandler begrebet livskvalitet og patienter, der lever med atrieflimren. I videnskabelig sammenhæng er det derfor til stadighed vigtigt at efterspørge definitioner af begrebet og argumenter for at anvende det.

Artikel 2 viser, at deltagere i undersøgelsen Kost, Kræft og Helbred, der er diagnosticeret med atrieflimren og/eller atrieflagren, rapporterer en lavere helbredsstatus, hvad angår fysiske elementer, sammenlignet med de øvrige deltagere

i kohorten. Desuden fremhæves betydningen af at forholde resultater indhentet på baggrund af standardiserede spørgeskemaer til den individuelle patients situation.

Artikel 3 illustrerer, hvordan det at balancere ansvar, at navigere i sundhedsvæsenet, at tilvænne sig situationen med at leve med atrieflimren og at have svært ved at genkende kropslige reaktioner er essentielt for oplevelsen af patientforløbet med nylig diagnosticeret symptomatisk atrieflimren. Undersøgelsen belyser desuden, hvordan disse oplevelser er forbundet med helbredsstatus målt ud fra standardiserede spørgeskemaer.

Afhandlingen konkluderer at:

Patienter, der lever med atrieflimren, har behov for individuel pleje og behandling. Individualisering er derfor nødvendig for at kunne tilbyde patienterne pleje og behandling af høj kvalitet.

Det har stor betydning for menneskets værdighed at anerkende, hvordan patienters perspektiv af at leve med en kronisk lidelse kan pendulere mellem en følelse af sygelighed og sundhed. Respekt for patientens værdighed kan forstærke dennes mulighed for at balancere ansvar og varetage autonomi.

Der stilles derfor krav om et personcentreret og holistisk syn på patientforløbet som en forandringsproces (transition) og som en helhed, også på tværs af sektorovergange i sundhedsvæsenet.

Afhandlingen bidrager med viden om den synergi, der kan opstå ved at betragte patienters levede erfaringer som et samlet hele med selv-rapporteret helbred, for dermed at opnå både et dybdegående og omfangsmæssigt indblik i, hvordan det opleves at leve med atrieflimren. Denne viden er essentiel for sundhedsprofessionelle, der beskæftiger sig med patienter, som lever med atrieflimren og andre kroniske lidelser, på tværs af organisatoriske sektorovergange.

LIST OF PAPERS

Paper 1

Høgh V, Delmar C, Riahi S, Frederiksen K. Quality of Life - Exemplified through Patients Living with Atrial Fibrillation. *J Nurs Care* 2014;03. doi:10.4172/2167-1168.1000150.

Paper 2

Hoegh V, Lundbye-Christensen S, Delmar C, Frederiksen K, Riahi S, Overvad K. Association between the diagnosis of atrial fibrillation and aspects of health status: a Danish cross-sectional study. *Scand J Caring Sci* 2016;30;507-517. doi:10.1111/scs.12272.

Paper 3

Hoegh V, Cummings EA, Riahi S, Lundbye-Christensen S, Frederiksen K, Delmar C. A year in the life of a person recently diagnosed with atrial fibrillation in Denmark. *Int J Pers Cent Med* 2015; 5: 166–181. doi:10.5750/ijpcm.v5i4.533.

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CHAPTER 1. INTRODUCTION

This dissertation investigates the patient perspective of the journey of living with atrial fibrillation (AF) with focus on lived experience, quality of life and self-reported health.

The journey of living with AF involves contacts with the healthcare system (hospital, community care and general practice) related to AF, and how AF influence on the patient's life and health. Therefore, the patient journey includes both significant events in daily life, family life and work life for the unique human being, and events related to contact with the healthcare system. Patient's lived experience and how AF impact on the patient's body and self-reported health, assessed from standardised questionnaires on populational as well as individual level, is of interest. The patient perspective thereby deals with the patient's lived experience of daily life, family life, and work life, quality of life and self-reported health status.

Recording a holistic view on the journey is central for this dissertation. Therefore, the perspective of the patient is important, because the patient is the only one who experiences the journey all the way. Healthcare professionals are often only involved in fragments.

Reflecting a holistic view on the patient perspective involves context, magnitude and various complex aspects, based on both qualitative and quantitative data sources. A study design, which can embrace complexity, context and magnitude, is needed. A case study design, which can embrace complexity, context and magnitude, is needed. A case study design is therefore applied (Yin 2014). The study is based on a systematic reflection and a literature review as a theoretical base, which is essential for a case study (Yin 2014).

The theoretical base for this dissertation is related to inconsistency in the use of the concept of quality of life, health-related quality of life, and health status in the scientific context concerning patients living with AF. With more than 100 different definitions, there is no consensus on a final definition of the concept of quality of life

(Bergland & Narum 2007). Additionally, labels of quality of life, health-related quality of life, and health status are used inconsistently and as synonyms. This inconsistency is evident in the context of scientific research literature in general and specifically related to the patient perspective of living with AF. The patient's unique lived experiences of daily life and of quality of life is thus at risk of being aligned with health-related quality of life and health status, with the risk of reducing the patient's lived experience on daily life, family life and work life to components related to AF. The concept of quality of life originally contained subjective unique elements, and more than health-related quality of life and health status (Hamming & Vries 2007; Moons 2004). Thus, health is an important component of quality of life in regard to being characterised as a patient in the healthcare system, and within the context of nursing care. Therefore, related to interpretation of self-reported health, it is important to bear in mind that even though it is evaluated in a standardised way using a questionnaire, it is dynamic and influenced by experiences, expectations, resources, and other people's stance (Thorgård 2009; Lunde 1993; Maruish 2011). Self-reported health assessed solely through standardised questionnaires, with predefined questions, not allowing unique variation and descriptions of aspects related to lived experience, might lack details on context related to the unique patient situation. In this dissertation, self-reported health is defined by the way patients report their state of health in a standardised way from a questionnaire, and thereby one of several essential components of quality of life (Bergland & Narum 2007). As it is not a desire to judge and clarify the prior inconsistent use of labels for self-reported health it will therefore be referred to as they are used in the specific texts.

The population of patients living with AF is heterogeneous in terms of age, gender, type of and burden from AF (Camm et al. 2012). This high heterogeneity in the patient population creates methodological challenges in population-based studies on self-reported health. Thus, quality of life is seen as being impaired for the majority of patients living with AF (Aliot et al. 2014; Thrall et al. 2006), in line with patients living with a structural heart disease (Dorian et al. 2000), and worse than patients with

common forms of atrioventricular re-entry supraventricular tachycardia (Lioni et al. 2014).

In clinical practice, AF was previously considered as not being an immediate life-threatening condition. Today, caring for these patients is thus considered a time-consuming and complex expert task (Berti et al. 2013). This is potentially due to an increasing focus on individualisation (Good & Rogers 2012; Camm et al. 2012) based on the individual patient's situation as a whole. Descriptions of lived experience reveal feelings of being neglected, overlooked and struggling to manage daily life with the disease (McCabe et al. 2015; Ekblad et al. 2012; Thrall et al. 2006).

The patient journey is based across sectors (the hospital, the community and general practice), which increases the risk of fragmentation in terms of logistics and organisational aspects. A connected patient journey is suggested to be an indicator of a high quality of care both nationally (Jansbøl 2014) and internationally (WHO 2006; Davies 2015). Nevertheless, complexity of the patient journey is likely to increase the risk of fragmentation. Fragmentation can lead to lack of healthcare professional ownership of the patient's journey. Furthermore, such fragmentation can result in creating silos in the healthcare service delivery: thereby, leading to a disconnected patient journey. Discontinuity in care is thereby a threat to high quality of care.

A large increase in the prevalence of AF within the next decades is expected (Ball et al. 2013). This requires rethinking, evaluation and likely development of new and more comprehensive ways of caring for patients with AF in the future (Aliot et al. 2014). With the patient journey being based across organisational sectors in the healthcare system, and an expanding and heterogeneous population of patients requesting individualised care and treatment, this rethinking is challenging. Through this dissertation, with a holistic view on the patient journey, I want to elaborate on the full story of the patient perspective, in order to facilitate this future challenge and change.

CHAPTER 2. BACKGROUND

As the theoretical base of the case study design (Yin 2014), I will identify what is already known and what needs to be further explored, in relation to the patient perspective of living in the journey with AF. The section consists of two parts. Firstly, I elaborate on the context related to AF, because knowledge on the disease is an important base position for nursing care. However, with a holistic view, this knowledge cannot stand alone but needs to be related to how patients experience life in the journey with AF. Then I present existing knowledge and gaps related to quality of life, self-reported health and lived experience. Throughout the process of performing research for the dissertation in itself and papers (Paper 1-3), I have performed several ongoing systematic literature searches, that were regularly updated. The latest update was performed on 17 March 2016, to ensure inclusion of all relevant research. Details related to the updated search will be presented in the second part of this section in order to display my process of working with the literature throughout the research process.

2.1. ATRIAL FIBRILLATION

AF is a complex and challenging condition, due to:

- an expected significant increase in prevalence in the near future,
- a heterogenic patient population in terms of; age, gender, symptoms, type of AF, risk factors, and treatment, and
- a journey across organisational sector boundaries in the healthcare system.

Being the most common admission-demanding cardiac arrhythmia of the atria of the heart and affecting 1-2 % of the global general population (Camm et al. 2012), AF is a significant health burden. Due to advancing age leading to an expanding elderly population, increase in the prevalence of cardiovascular diseases, increase in obesity and metabolic syndrome, and a likely underestimation of the disease, the prevalence

of AF is expected to increase dramatically within the next decades (Ball et al. 2013; Rahman et al. 2014).

Differences in age and gender of patients with AF are well documented, with men tending to be diagnosed with AF earlier than women (Rich 2009; Feinberg et al. 1995). Nevertheless, the prevalence in women increases with increased age. Symptoms range on a continuous scale from no sensation to strong dyspnoea, tiredness and palpitations (Camm et al. 2012). Asymptomatic AF offers a special challenge because it is harder to detect and thereby to treat, but untreated it implies the same risk of stroke as symptomatic AF (Glotzer & Ziegler 2013).

Based on symptoms, AF is defined by five types:

- Patients **first diagnosed with AF**
- **Paroxysmal AF** is self-terminating, usually within 48 hours
- **Persistent AF** is present when an AF episode either lasts longer than 7 days or requires termination by cardioversion, either with drugs or by direct current cardioversion
- **Long-standing persistent AF** has lasted for ≥ 1 year when it is decided to adopt a rhythm control strategy
- **Permanent AF** when the presence of the arrhythmia is accepted by the patient and physician.

AF shows a variation from being “lone AF”, as in 30% of the population, to being influenced by multiple cardiovascular conditions (Camm et al. 2012). Despite some cases where the cause of AF cannot be located, AF is usually associated with serious comorbidity, for example: chronic kidney disease, dementia, myocardial infarction, and metabolic conditions. With AF, there is a twofold higher risk of death, threefold increased risk of developing congestive heart failure, and fivefold increase in the incidence of cerebral apoplexy/stroke when compared with people in sinus rhythm (Rahman et al. 2014; Hasun et al. 2014; Camm et al. 2012).

AF is a chronic condition, and despite a high adherence to treatment, relapse rate and treatment failure is high. Nursing care and treatment of AF patients are thereby not only intended as a cure, but also as a means of supporting the patients to manage daily life with their condition. As emphasised in several earlier studies (Lüderitz et al. 2000; Lane & Lip 2009; Jenkins & Bubien 1996), it is vital to support the patients in order to achieve a high quality of life.

It is suggested that treatment strategies for AF should be personalised, based on the patient's specific situation, with symptom burden, type of AF and risk stratification for stroke and bleeding (Kirchhof et al. 2013b). Multiple and continuously developed treatment options are offered to the patients and requires individualised support and information be provided to the patients by the healthcare professionals. A patient-centred treatment and care approach focusing on the importance of stroke prevention and interdisciplinary collaboration including nursing care, has recently been recommended (Good & Rogers 2012; Berti et al. 2013).

The patient experiences of living with AF extends across organisational sectors in the healthcare system. In the primary sector, attention is given to regulation and monitoring of oral anticoagulant treatment, and in the hospital sector, attention is given to regulation of medical arrhythmic treatment, direct current cardioversion, and the newly developed radio frequency ablation (Camm et al. 2012).

Peculiar for the condition with AF is that it is a chronic and serious condition. Despite, the condition is likely to be 'invisible' to others (e.g. for healthcare professionals, family and friends) and potentially also for a patient with asymptomatic AF. However, especially untreated the condition of AF can be potentially life threatening. For some patient's the conditions of AF leads to significant restrictions in their life. With the limited success of treatment for AF, and high relapse rate despite adherence to treatment, living with the condition of AF is a special challenge at risk of being overlooked in clinical practice (McCabe et al. 2015; Ekblad et al. 2012; Thrall et al. 2006).

2.2. LITERATURE REVIEW

In order to identify existing knowledge and gaps from the context related to the patient perspective concerning quality of life, self-reported health and lived experience, in patients living with AF, I performed a literature review inspired from the approach described by Polit and Beck (2013). The systematic literature search was based on the following research question:

- How is the patient perspective – departing from the concept of quality of life, including lived experience and self-reported health status – described and reported by patients living with AF?

The following six bullet points summarise the results from this literature review.

It is well known that:

- the concept of quality of life is widespread and multidimensional
- methodological limitations due to low sample size, lack of control group, and use of valid assessment tools are common in the context of patients living with AF
- descriptions of lived experience of living with AF reveal information on being neglected, experiencing an unpredictable physical ability, delay in diagnosis, and struggles with interpretation of symptoms and obtaining the needed support

We need to know more about:

- the consequences of the inconsistent use of the concept in a scientific context
- patients self-reported health from studies allowing for relevant stratification and adjustment related to the heterogenetic patient population, and relating estimates to the general population

- the patients' lived experience and perception of self-reported health status across organisational sector boundaries over time

Search strategy, inclusion process and the process of analysing papers to achieve these results, will be presented in the following section.

2.2.1. SEARCH STRATEGY, INCLUSION AND ANALYSIS OF PAPERS

Systematic literature searches in CINAHL, PubMed, and Web of Science last updated on 17 March 2016, were done assisted by a librarian from the Medical Science Library at Aalborg University Hospital. Because there is no generic term for the patient perspective of quality of life, search terms such as: 'patient compliance', 'patient satisfaction', 'patient lived experience', 'patient experience', 'patient perception', 'patient view', 'narratives', 'nurse-patient relation', 'health status', 'self-assessment' and 'health' were used in combination with 'atrial fibrillation' and 'quality of life'. Specific search terms are displayed in Appendix A.

CINAHL indexes literature from hundreds of nursing and allied health journals in English, as well as book chapters and dissertations. MEDLINE accessed via PubMed website, contains the primary source of information on the biomedical literature (Polit & Beck 2013). Web of Science provides access to multidisciplinary science (Thomson Reuters 2016). By combining these three databases, I expect to achieve access to knowledge with important contributions for covering the research context related to the patient perspective of the journey of AF. A total of 4,213 papers were returned.

Software from Mendeley (2016) was used in the process to manage and systematise the large amount of papers. A total of 29 papers were included in the review. An overview of the included papers is displayed in Table 1.

Table 1. Included papers in the review.

<i>Number of papers</i>	<i>Type of papers</i>	<i>References to papers</i>
10	Research reviews	(Jenkins & Bubien 1996; Lüderitz et al. 2000; Engelmann & Pehrson 2003; Gronefeld & Hohnloser 2003; Schron & Jenkins 2005; Thrall et al. 2006; Lane & Lip 2009; Aliot et al. 2014; Zhang et al. 2015; Mark 2016)
1	Scientific statement	(Rumsfeld et al. 2013)
6	Scientific research papers based on qualitative data	(McCabe et al. 2011; Ekblad et al. 2012; Withers et al. 2015; Dalteg et al. 2014; Altiok et al. 2015; McCabe et al. 2015)
12	Scientific research papers based on quantitative data	(Steg et al. 2012; van den Berg et al. 2001; Dorian et al. 2000; Roalfe et al. 2012; Bohnen et al. 2011; Perret-Guillaume et al. 2010; Kang & Bahler 2004; Ariansaena et al. 2009; Lioni et al. 2014; Maryniak et al. 2006; L. Ong et al. 2006; Dagues et al. 2007)

The selection process started with screening of all titles in order to include relevant papers. Because the literature review is interested in quality of life, self-reported health status and lived experience, papers with both qualitative and quantitative data sources are of interest. A flowchart of the process of inclusion and exclusion of papers is displayed in Appendix B.

Inclusion criteria: Papers were included if they were scientific research papers and able to contribute with information and understanding of the patient perspective of quality of life including patients' lived experience and perception of self-reported health status. Research reviews were also included, keeping in mind that reviews are secondary data (Polit & Beck 2013) and thereby interpretations summaries of the primary data. Reviews provide an overview of existing and available scientific knowledge. They were therefore expected to provide an overall background for this dissertation, which is important as this is a large area of research.

Exclusion criteria: Table 2 display reasons for exclusion. Additionally to the reasons in Table 2, 49 papers were excluded due to lack of available title and abstract and 70 papers were excluded due to no available full-text in English. Nineteen papers involving editorial material and eight papers of poster abstracts were excluded as the interest for this literature review was on scientific research papers and reviews.

Table 2. Excluded papers in the review.

<i>Number of papers</i>	<i>Interest in the hit</i>	<i>Reason for exclusion</i>
799	Investigating treatment development, interventions, pacemakers, cardioversions and implantable cardioverter defibrillators.	Evaluation of treatment interventions was not the focus for this dissertation.
108	Heart surgery and Maze operations.	Treatment concern is not of interest for this dissertation.
647	Medication and anti-coagulant treatment and rate versus rhythm strategy treatments.	
333	Radiofrequency ablation.	
66	Involving guidelines and consensus statements related to treatment for AF.	
23	The effect of physical exercise training.	
64	Perspectives on patient education.	The focus of this dissertation is on the patient perspective and not directly on the relation between the patient and the healthcare professional. Therefore, these papers were excluded, because they deal with the relation between the patient and the healthcare professionals.
20	Psychological distress, stress management and illness belief.	These papers involve causal and predictive factors, which can provide impact on quality of life. In this dissertation, I am interested in quality of life as a phenomenon in itself, and how it is described, to affect the patient's life.
6	The epidemic of AF.	AF is an escalating epidemic; however, this epidemic in itself and risk factors related to developing AF are not the focus of this dissertation.
320	Risk factors related to AF.	
164	Related to heart failure, as a central comorbidity to AF.	These papers focused on the perspective of the disease and not the patient perspective.
16	Pathophysiology of AF.	
6	Silent AF.	
36	Symptoms related to AF.	The patient perspective and not the economic perspective of AF is of interest.
49	Involving cost-utility, cost-effectiveness and cost-benefit analysis and economic perspectives related to AF.	
16	The development and validation of disease-specific questionnaires for patients living with AF.	Despite the growing interest in development and validation of questionnaires, this is not the focus of this dissertation.
2	Discussing perspectives on the use of technology to collect and share information on quality of life in patients with AF.	Not in focus for this dissertation.
2	Concerning children.	
14	Concerning athletes and long endurance sports.	
45	Concerning public health implications for elderly cardiac patients.	This dissertation is focused on the patient perspective departing from nursing care, and not public health.
1	The perspective from relatives.	The focus for this dissertation is on the patients experience, not the relatives.

In order to locate additional papers of relevance, references of the included papers were further investigated, resulting in inclusion of one scientific paper evaluating health-related quality of life and exercise capacity in elderly patients with permanent AF as compared with participants without AF, based on a cross-sectional design (Ariansena et al. 2009).

The Critical Appraisal Skills Programme (CASP) (CASP UK 2016) and Strengthening the Reporting of Observational studies in Epidemiology (STROBE) (Vandenbroucke et al. 2007) were used in assessment of included papers. The process revealed information on the papers strengths and limitations, with an overall acceptable level of quality for including the papers in the review.

In order to identify gaps in the knowledge, the included papers underwent a thematically analysis. The analysis was performed from suggestions for thematically analyses of substantial and methodological themes in a literature review described by Polit and Beck (2013). A substantially theme is concerned on patterns, consistency and gaps in the knowledge provided from the papers. A methodological theme is concerned on methods used to address the research question, and the method's strengths and limitations. Both substantially and methodological patterns are of interest for this dissertation. Inspired by the research question for the review, the analysis were structured from the three themes: Theme no. 1. The concept of quality of life. Theme no. 2. The patients' self-reported health status. Theme no. 3. The patients' lived experience. A schedule including aim, design, results, contribution-/gap, aspects of the patient perspective and comments related to CASP or STROBE was used for systemising information from all included papers. An example of such a schedule is displayed in Appendix C. An overview of aim, design, key result and comments on the papers strengths and limitations for included papers applied as a working tool in the analysis process are provided in Appendix D.

Descriptions of the three themes as results and findings from the literature review will be presented in the following section.

2.2.2. THE PATIENT PERSPECTIVE OF QUALITY OF LIFE WHEN LIVING WITH AF

2.2.2.1 The concept of quality of life

Several studies in the context of the patient perspective apply the concept of quality of life. Quality of life is thereby documented to be widely applied for elaborating the context of the perspective of the patients (Mark 2016). According to the literature review by Mark (2016), applying the concept of quality of life to express the patient's perspective of living with AF is challenging, because the concept in itself is multidimensional and complex and therefore has been understood in a variety of different ways. According to the World Health Organization, the concept of quality of life is defined as: '*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*' (WHO 1997, p.1). Although few people would debate its importance, there is no final consensus on a definition (Mark 2016).

In the medical context, as debated by Lane and Lip (2009) as well as Engelmann and Pehrson (2003), quality of life is often focused on health, and the impact on a person's physical condition and role, psychological well-being, social activities and everyday activities, rather than more general notions as overall life satisfaction and living standards.

The importance of definitions of, and arguments for, using the concept has been emphasised in the context for long (Engelmann & Pehrson 2003; Lüderitz et al. 2000; Jenkins & Bubien 1996). Accordingly, lack of definitions and descriptions of reasons for applying the concept of quality of life has earlier been reported as a limitation (Schron & Jenkins 2005; Jenkins & Bubien 1996; Lüderitz et al. 2000).

Major concerns and struggles related to using the concept of quality of life have earlier been discussed by Mark (2016) in the overall context of cardiovascular diseases. AF

is embedded in this context. The struggles relating to applying the concept are thereby major concerns for the context of cardiovascular diseases, not only for patients living with AF. Labels and abbreviations for health-related quality of life, health status and quality of life, being applied inconsistently and sometimes as synonyms, are likewise reported by Mark (2016). As further emphasised by Mark (2016), the Food and Drug Administration introduced requirements for applying quality of life as outcome in clinical studies in the mid-1980s, by successfully approving new cancer drugs based on patient-reported quality of life outcomes. At that time, especially psychologists and sociologists debated how the concept of quality of life was likely to be turned into a measurable construct. This debate has been related to unrealistic expectations of what type of knowledge can be provided from a given method, e.g. a standardised questionnaire (Mark 2016). As early as in 1996 Jenkins and Bubien addressed the struggles referring to a goal of defining the undefinable and observing the unobservable. Despite continuous development and validation of disease-specific questionnaires designed for patients with AF (Aliot et al. 2014), and for cardiovascular patients in general (Mark 2016), it remains a challenge to measure quality of life. However, as suggested by Gronefeld and Hohnloser (2003) clear descriptions of the concepts, consistency in labels applied, and clarity of what aspects of quality of life are of concern are important for preventing misinterpretation of results. A discussion of the consequences of lack of definitions, argumentation potentially leading to inconsistent use of the concept of quality of life in the context of patients living with AF is therefore important. Such discussion has not been identified from this literature review.

2.2.2.2 The patients' self-reported health status

According to a scientific statement on patient reported outcomes related to the context of cardiovascular diseases (Rumsfeld et al. 2013), aiming to describe key aspects of the patient's health status reviews and advocates for patient-reported health status in cardiovascular health, the patients' self-reported health status is complex. Self-reported health include three dynamic domains: symptom burden, functional status, and health-related quality of life. Despite the fact that consensus on quality of life is

an important outcome in studies, patient-reported outcomes elaborating the patient perspective of quality of life are not measured in all clinical studies (Rumsfeld et al. 2013). Lack of familiarity with, and interpretation of, quality of life measures and an unrealistic expectation of what they can add to existing knowledge have been suggested as barriers of applying the concept (Mark 2016).

Previous studies have been tempered with major methodological weaknesses in terms of sample size, lack of control group, short term follow-up and use of non-validated assessment tools (Thrall et al. 2006; Zhang et al. 2015; Aliot et al. 2014). Despite these limitations, results indicate significantly poorer health-related quality of life and self-reported health status in patients with AF compared with healthy controllers (Dorian et al. 2000; Perret-Guillaume et al. 2010; van den Berg et al. 2001). Moreover, worse than in patients with re-entry atrioventricular supraventricular tachycardia (Lioni et al. 2014), and similar to that of patients with structural heart diseases (Dorian et al. 2000). Both physical components related to limitations in daily activities due to tiredness, breathlessness and palpitations (Steg et al. 2012) and mental components of health status related to unpredictability in relapses, anxiety and depression (Perret-Guillaume et al. 2010; Lioni et al. 2014) are seen as impaired. Additionally, the perceived quality of life in spouses is affected similar to that in the patients (Bohnen et al. 2011).

Several studies support the notion that the population of patients living with AF is heterogeneous in terms of gender, age, type of AF, comorbidities and burden from symptoms (Engelmann & Pehrson 2003; Thrall et al. 2006; Lane & Lip 2009). Previously reported methodological challenges due to sample size, access to an adequate control group, adequate time dimension and selection of a valid assessment tool are most likely related to this heterogeneity. The sample size needs to be sufficient to allow relevant stratification and adjustments for potential confounding and effect measure modification on the association between AF and patient self-reported health status. Low sample size has been reported as a limitation in seven earlier studies (Dorian et al. 2000; van den Berg et al. 2001; Kang & Bahler 2004; Ariasena et al. 2009; Perret-Guillaume et al. 2010; Maryniak et al. 2006). Low statistical power can

lead to difficulties in performing adequate statistical tests to enable relevant adjustments and stratification. As far as the association between AF and self-reported health status is concerned, gender (Ong et al. 2006; Dagres et al. 2007; Lane & Lip 2009) and age (Bjoerner et al. 1997; Maruish 2011; Ariansena et al. 2009; Dagres et al. 2007; Ong et al. 2006) are considered as effect measure modification and comorbidity as potential confounding (Maruish 2011). For example, a recently published cross-sectional study on the elderly population of patients living with AF shows that AF had little impact on generic health status when comparing with norms from the general population, and in the absence of comorbidity (Roalfe et al. 2012). Despite the large sample size in the study (N=1,762), there was a lack of information on comorbidity related to the general population norms. In this study, it was therefore not possible to elaborate further on this issue. Previous reviews have therefore emphasised the importance of an adequate study design for studies investigating the patient self-reported health status related to living with AF (Engelmann & Pehrson 2003; Mark 2016; Aliot et al. 2014). Such a study has not been located from this literature review.

Another issue is that using one generic assessment tool might miss out essential aspects of the patient perspective of health-related quality of life (Zhang et al. 2015) because it has a general focus, not specifically on AF. Study endpoints such as symptom burden (Dorian et al. 2000; van den Berg et al. 2001), functional status (Steg et al. 2012), exercise capacity (Ariansena et al. 2009), anxiety and depression (Lioni et al. 2014; Ong et al. 2006) have been suggested in order to capture the impact of AF on the patient's self-reported health.

In 2006, Thrall et al, systematically reported methodological issues and challenges related to the research field. Accordingly, these methodological issues and challenges especially due to internal validity, has newly been debated by Zhang et al. (2015) as a reason for moderate quality of studies on health-related quality of life in patients living with AF. Methodological considerations thereby remain relevant. For example, as stated by Zhang et al, no double-blinded randomised controlled studies were included in their research review. This issue is likely to illustrate the complexity of

the association between AF and patients' self-reported health status, and the difficulty of designing a study with this type of design. The association request for a research design that can embrace its complexity.

Supported by several studies, another significant issue has been lack of discussion on the interpretation of results. In two earlier studies (van den Berg et al. 2001; Lioni et al. 2014) there is lack of discussion on when a statistical significant result is clinically meaningful. In the cross-sectional study by Dorian et al. (2000) a standard deviation of 0.5 is defined as a significant change in the scales of Short From 36 (SF-36). Today, recommendations are available for SF-36 (Maruish 2011), but defining a minimal clinically meaningful difference in a health status score, thus, depends upon the specific patients' appraisal of their overall situation. Moreover, Engelmann and Pehrson (2003) earlier emphasised the need for providing the participants with an opportunity to evaluate their overall appraisal of quality of life.

Studies with larger sample sizes, N=10,523 (Steg et al. 2012), N=5,333 (Dagres et al. 2007), N=1,762 (Roalfe et al. 2012), on the association between AF and patients' self-reported health status have been performed in recent years. These studies are based on the EQ-5D, a health utility scale, and not a direct health status assessment tool. One study performed in an elderly population (>75 years) additionally applied the generic tool SF-12 (Roalfe et al. 2012). Another study included functional status (Steg et al. 2012) as an additional study outcome, and the third study was mostly concerned on gender difference related to the association between AF and self-reported health status (Dagres et al. 2007). Only in one included study were norm data from the general population on self-reported health status with information on age and gender provided (Roalfe et al. 2012). None of these studies contributed with information from the general population in order to evaluate the influence from comorbidity, on the association between AF and self-reported health status.

Despite development and validation of a variety of different assessment tools, both generic and disease-specific, there are no ideal techniques for assessing health-related quality of life or self-reported health status in patients diagnosed with AF (Aliot et al.

2014). However, as earlier suggested in the review by Engelmann and Pehrson (2003), using both generic and disease-specific assessment tools is recommended. Accordingly, emphasis has been directed towards assessing self-reported health status in more than one point in time, asking the participants to give an overall appraisal of their quality of life.

2.2.2.3 The patients' lived experience

Studies based on qualitative data exploring the patients' lived experience have evolved in recent years, but are sparse compared with studies on the development and evaluation of treatment interventions.

From four qualitative interview studies by McCabe et al. (2011; 2015), Ekblad et al. (2012) and Withers et al. (2015) daily life with AF is reported to be characterised by unpredictability related to symptoms, and the onset of a new 'attack'. Based on interviews with 12 couples in a grounded theory study (Dalteg et al. 2014), not only uncertainty for the patients but also for their relatives is reported. Daily life for patients with AF is constantly changing and tempered with a changing physical ability to maintain daily activities. Three of the included studies report patients experience feeling uninformed and unsupported, struggling to be believed (McCabe et al. 2015; Withers et al. 2015; Altiok et al. 2015). Furthermore, that the patients experience delay in diagnosis, their concerns being marginalised and counselling on the nature of AF and support to be lacking (Withers et al. 2015; Ekblad et al. 2012). Two qualitative interview studies report that the patients tend to misinterpret symptoms and find it challenging to obtain balanced and uniform information from healthcare professionals on how to manage life with AF (Altiok et al. 2015; McCabe et al. 2015). Despite a daily life with worries, fear and anxiety about the occurrence of a new attack will occur, in the two studies performed by McCabe et al (2015; 2011) the patients report hope for a better future without AF.

The review support evidence that the constant fear and unpredictability are affecting all aspects of daily life, family life and work life: Daily life is affected by reduced physical activity and social interaction leading to isolation (Withers et al. 2015;

McCabe et al. 2015). Family life is affected by a feeling of guilt when help to maintain daily activities is needed – for instance for carrying groceries and due to unpredictable physical ability, some patients dare not be alone minding their grandchildren (Withers et al. 2015). Thus, AF is a burden, not only for the patients, but also for their significant others. For some patients, work life is affected by a tendency to hide their symptoms at work and a feeling of being pushed to retire before time, because the condition makes it too stressful to maintain their jobs (Withers et al. 2015). Potential changes related to work life and frequent check-ups in the hospital and in general practice accordingly imply a financial burden (Altioik et al. 2015).

Common for the studies based on data from qualitative interviews is that data have only been collected at one point in time, except in one study (Dalteng et al. 2014) where follow-up interviews with patients and relatives had been performed. All studies were connected to hospital-related care and treatment. As emphasised by Schron and Jenkins (2005) longitudinal studies focused on the patients' perspective of lived experience and self-reported health, and how this lived experience and perception change over time are missing in the existing literature. A connected patient journey, also across organisational sector boundaries providing patients with connected treatment and care is considered desirable to enhance the quality of care. Accordingly, no longitudinal study investigating the patients' lived experiences across organisational sector boundaries has been identified from this review.

This literature review shows that interventions for treatment of AF have been of considerable interest in the research field related to quality of life in patients living with AF (Thrall et al. 2006; Zhang et al. 2015). However, the impact from the arrhythmia on the patients' life needs to be further elaborated (Lane & Lip 2009). Even though previous studies can provide an overview of the impact of AF on health-related quality of life and self-reported health status, there is a lack of descriptions of the patients' lived experience. A gap remains between the parameters currently used to assess patients' self-reported health status in clinical studies and the descriptions of lived experience needed in order to incorporate the specific patient's situation as a whole. Several studies has suggested a qualitative approach for this purpose (Zhang

et al. 2015; Mark 2016; Engelmann & Pehrson 2003). Moreover, a combination of qualitative and quantitative data and methods has been suggested in order to access the ‘full story’ of the patient perspective of living with AF (Mark 2016). Qualitative data on in-depth description of the human life to understand lived experience. Quantitative data on self-reported health status to be able to access the magnitude of the health burden related to AF. Neither qualitative nor quantitative data alone can provide the ‘full story’ of the patient perspective (Mark 2016). No study in this context has earlier combined qualitative and quantitative data to illuminate the patient perspective of quality of life in the journey of living with AF.

2.2.3. GAPS FROM THE LITERATURE

To access ‘the full story’ of the patient perspective, a design including both qualitative and quantitative data and the patient journey as a whole across organisational sector boundaries is needed.

The concept of quality of life is widespread and multidimensional, which calls for definition and argumentation when it is applied in a scientific context. This is important in order to clarify aspects of the concept of concern in a given study. Definitions and argumentation applied in the context of the patient perspective of living with AF, and consequences of inconsistent use of the concept, need further elaboration.

Due to the heterogeneous patient population and a list of methodological weaknesses, including low sample size, lack of control group, and use of valid assessment tool, it has been difficult to perform studies allowing stratification and adjustment for effect modification and potential confounding on the complex association between AF and self-reported health status. Additionally, estimates on the association need to be related to the general population in order to elaborate on issues of effect measure modification and potential confounding.

A study with a longitudinal design is required in order to access the patients' lived experience and self-reported health-related to daily life, family life and work life over time.

CHAPTER 3. AIM AND RESEARCH QUESTIONS

Based on the literature review, the aim of this dissertation is to explore the complexity and magnitude of the context related to the patient perspective of living in the journey of AF, including quality of life, self-reported health status and lived experience.

The dissertation is based on the following research questions:

- How is the concept of quality of life defined and argued for in the scientific research context of patients living with AF, and with what consequences?
- How is being diagnosed with AF associated with self-reported health?
- How are lived experience and self-reported health-related to quality of life expressed in a one-year patient journey of AF
 - on the individual level
 - related to daily life, family life, and work life
 - across boundaries between sectors in the healthcare system?

CHAPTER 4. ONTOLOGY

Elaborating on the patient perspective calls for reflections and considerations on human existence. Therefore, I will describe the ontological stance of this dissertation, which provides a holistic worldview stating that humans are *like all others, like some others, and like no others*.

This stance is inspired by the philosophy of phenomenology – the study of phenomenon, as it shows itself in the world (Van Manen 2014; Merleau-Ponty 1962). Phenomenology was originally described in the works of German philosophers Husserl (1859-1938) and Heidegger (1889-1976) and implies multiple stands and traditions. Only aspects of specific interest for illuminating the worldview of this dissertation are elaborated.

According to the work of French philosopher Merleau-Ponty (1908-1961) on the phenomenology of perception (1962), human beings are embodied into the world. It is through our senses that we perceive the world. The body thereby embraces, and constitutes, the world. We all belong to the same world, in a pre-consciousness perception and interaction with the ‘flesh’ of the world, culture and environment (Van Manen 2014, p.128). In that sense, we are connected to everyone and everything in the world. The world exists – is always already there – in itself, e.g. in the human body and material things surrounding the human being. Merleau-Ponty acknowledges universal biological components and patterns of the human body, related to being a biological organism, which, in some cases, can be identified as objects because the body and its parts can be observed, both by the person itself and by others. In that sense, the body is a vehicle for the soul (Merleau-Ponty 1962, pp.73–89). However, his concern is that the human being is not only an object as a biological organism, but a lived body – one’s own body. This lived body is dialectically and inseparably connected to the mind. This connection is characterised by a double sensation, by being ‘feel able’ and being ‘able to feel’ (Merleau-Ponty 1962, pp.90–97). Being a body is consistent with a holistic view of the patient journey including lived

experience and self-reported health status. The stance of being a lived body thereby contributes a unifying understanding of human existence, as a lived body, considered a change from the historical dualistic gap between the objective body and the subjective soul. Being in the world with the lived body has already created meaning, even before conscious reflection. In that sense, relation to the world is corporeal more than intellectual. With humans' lived experience being relational, corporeal, material, temporal and spatial, they experience their world through five essential life existentials: lived self-other, lived body, lived things, lived time and lived space (Van Manen 2014, pp.302–307). These are universal and typical life phenomena as they belong to everyone's life world. A holistic worldview thus implies being an object with universal biological components and life existentials. With these universal typical patterns of the human being, *humans are like all others*.

Related to others and things, humans are subjects, as lived self-other (Van Manen 2014). This implies nature and culture in an always dialectic relationship. The body-subject perceives the world through perception, language, emotion and movement in time and space with others and things. Self-understanding is gained via the human lived body through relation to things and other humans. This relationality is a pre-reflective perception and experience. We can be touched by others and things. Moreover, other humans and things can speak to and with us (Van Manen 2014, p.130). Experiences of things can remind us of our responsibility, disappoint us, and reflect back our disappointment. This makes the things surrounding humans essential for their self-understanding and puts emphasis on the mutually important relation between humans and lived things. For example, in conversations with others, one can become aware of thoughts that one was not aware of. Reflection, as an intellectual process, is only possible because human existence is pre-reflective and always entwined into the world. Inspired by the work of French philosopher Emmanuel Levinas (1906-1995), van Manen elaborates on ethical dimensions of lived self-other. Feeling the appeal from another human or thing goes beyond consciousness. Responding to an appeal provided by another human is unmediated by intention and thinking. Feeling moved by an appeal from another human can move into non self-

centered action. The appeal of responsibility to act for the benefit and the good of another human can be direct (instinctively offering the person your hand to prevent the person from falling on a slippery sidewalk) or call for interpretation in a more complex way, confronting you with a question of how to make the decision of acting. The dialectic relationship between nature and culture is thereby evident for all human beings.

By sharing typical human patterns and characteristics in specific life situations related to the impact of living with a disease, *humans are like some others*. Related to AF, some patients share the same impact from symptoms and bodily reactions, for example breathlessness, palpitations, tiredness and dizziness. Some patients receive the same treatment, for example oral anticoagulant treatment, treatment related to heart frequency control and /or heart rhythm control, direct current cardioversions or radio frequency ablation. Some patients live with the same comorbid conditions, for example heart failure, stroke, renal diseases and diabetes. Feelings of anxiety and unpredictability associated with relapse of the arrhythmia, unpredictable symptoms and changing physical ability are also common characteristics and typical patterns in patients with AF. Knowledge of these typical and characteristic patterns is important in order to develop standards for nursing care and treatment (Berti et al. 2013).

People display both typical and unique patterns. People are involved in situations being a lived body and lived self-other. Thereby, both in their body and also in relation to their surroundings. By being included in situations, and in relation to others and things, people shape and represent situations. Situations therefore also include typical and unique patterns. Danish philosopher K.E. Løgstrup described the dialectic relation between typical and unique patterns of a situation. By referring to the ethics of the situation, he describes every situation both to contain typical patterns and to be unique (Løgstrup 1987). A situation might contain typical patterns recognisable from experience of another situation. However, with time being irreversible, every situation is unique, meaning that it will never reoccur in exactly the same form. Accordingly, this potential contrast is less of a problem, because this uniqueness is due to time being irreversible, and typical patterns are related to a content of a situation. In that sense,

time being irreversible contributes uniqueness to human lived experience. With the human existence being temporal and spatial, humans experience by living, in lived time and lived space, which puts emphasis on the uniqueness of the human lived experience. Temporal related to time being irreversible, and spatial related to the specific space surrounding the specific human being at a specific point in time. Humans interpret phenomena and life events from the source of subjective feelings, perceptions and sensations. Being in the world with things and other humans is therefore unique (Van Manen 2014). Unique in the sense that, despite typical human and biological patterns in the specific human lived experience, a subjective lived experience will never reoccur in exactly the same form, even for the same human being. This uniqueness implies that *humans are like no others*.

Knowledge of characteristics and typical patterns, and predictions for a specific patient group can therefore never be complete without information of the perspective of the specific patient's unique situation as a whole. Lived time and lived space are experienced differently depending on the specific context of a situation (Van Manen 2014). Moreover, with lived experience expressing the human life-world as a whole, referring to e.g. life-stories, interactions, social relations, values, wishes, plans, and goals for what the human wants to achieve (Thorgård 2009), the human life-world contains multiple meanings. Related to life with AF, human lived experience expresses both typical patterns and the uniqueness of the biological components and universal existential life-phenomena, and the uniqueness of the patient.

In nursing care, both typical patterns associated with the human life-world, human biology and health, and the uniqueness of every patient situation as a whole are central for a holistic worldview. This calls for a unifying acknowledgement and understanding of knowledge of:

- human biology and existence in general (*humans are like all others*)
- AF as a disease with typical symptoms, treatment and comorbidity (*humans are like some others*)

- the unique patient's lived experience of life with the chronic condition of AF, related to how symptoms, treatment, and bodily reactions may impact specifically on human daily life, family life and work life (*humans are like no others*).

Taking the inseparable body-subject and understanding of the complexity of human lives as a whole into account requires complex research processes. This statement is leading to the next section illuminating epistemological and methodological considerations on the design of this dissertation.

CHAPTER 5. METHODOLOGY AND DESIGN

This dissertation has a case study design, which has been a popular and widely applied design within multiple research traditions, also within nursing care (Yin 2014). A case study design allows retaining a real-world context and a holistic view on a ‘case’ of interest (Yin 2014). This is done by focusing on the case of interest, aiming to answer questions of ‘how’, embracing multiple data sources and thereby potentially conflicting paradigmatic understandings of knowledge (Yin 2014; Flyvbjerg 1991; Flyvbjerg 2001; Flyvbjerg 2006).

In a real-world context, the case study design is appropriate for elaborating on complex research processes involving context and complexity, and acknowledging the perspective of magnitude of human behaviours and organisational aspects. The need for elaborating on potentially conflicting understandings in this specific case study is emphasised in relation to the diversity of the concept of quality of life. Moreover, related to the patient perspective embracing both patients’ lived experience of being neglected and marginalised and self-reported health being impaired.

According to Yin (2014), the dissertation falls within the definition of a case study design, because it:

- is grounded in existing knowledge (demonstrated from the literature review in Chapter 2)
- aims to answer questions of ‘how’, of which the researcher has little control
- applies empirical data (need for empirical data to elaborate on the patient perspective)
- traces a phenomenon (the patient perspective) without clearly evident boundaries between the phenomenon and the context
- traces a contemporaneous phenomenon (living with) over time in its real-world context

- relies on multiple data sources and propositions (need for combining qualitative and quantitative data sources).

Depending on the case of interest, a case study design can be qualitative or quantitative or both (Yin 2014). For this dissertation, both qualitative and quantitative data are needed in order to embrace the full story of the patient perspective. The design is explorative in its origin, because no causal conclusions are the goal of the included data sources.

The case study design is based on phronetic science (Flyvbjerg 2001, p.140). The following section accounts for stances and considerations related to the epistemologically base of the study.

5.1. PHRONETIC SCIENCE

Phronetic science is closely related to practical wisdom and acknowledges the type of method and knowledge needed in order to elaborate on given research questions for a case of interest (Flyvbjerg et al. 2012). Inspired by Aristotle's philosophy, phronetic science acknowledges all aspects of knowledge; *episteme*, *techné* and *phronesis* (Flyvbjerg 2001, p.2; Aristotle 1976).

- Epistémé accounts for produced analytical scientific, ideal, universal, abstract, context-independent knowledge achieved by analytical rationality, and invariable in time and space (know why)
- Techné accounts for craft, art and instrumental pragmatic, technical, specific, variable and context-dependent knowledge (know how)
- Phronesis as practical wisdom accounts for reflective judgements and decision-making. A context-dependent and pragmatic knowledge based on what is good or bad for humans. A practical value rationality on how to behave, including ethics and deliberations about values (a practical common sense). Thereby, a prudence towards how to behave under specific circumstances. This knowledge and prudence are not equated with or reduced to a general truth.

In phronetic science, research is a matter of what matters to people, and less a matter of what method to use. This central issue requests respect for every relevant data source and method with rigour and transparency in order to elaborate on the case of interest (Flyvbjerg 2001, pp.53–65). Acknowledging the existence of context-independent universal knowledge in harmony with context-dependent unique interpretive knowledge has therefore lead to phronetic science being suggested as a means of bridging conflicting traditions in science (Flyvbjerg 2001; Flyvbjerg et al. 2012; Yin 2014). Being oriented towards action and practical ethics, prioritising the complex, particular and specific, phronetic science is essential to the holistic worldview in the context of nursing care.

The complexity and magnitude of the context of the patient perspective in the journey of AF open up for different scientific research traditions.

- Elaborating on the importance of definitions and argumentation in a scientific context when applying concepts in general calls for a critical interpretive and hermeneutical tradition (Gadamer 2007). This is particularly relevant for using the concept of quality of life, because it is diverse and multi-dimensional. Understanding based on one's pre-understanding is central within this tradition and calls for critical and systematic reflection based on one's own pre-understanding. With pre-understanding being part of one's own context, context is thus essential for knowledge. Within a hermeneutical tradition, emphasis is therefore put on context-dependent knowledge.
- Investigating the magnitude of the patients' self-reported health status on the population level requests knowledge of the epidemiological and bio-statistical tradition (Rothman 2012; Fletcher et al. 2014; Kirkwood & Sterne 2008). The interest in developing and applying methods that will minimise the risk of systematic errors and play of chance is based within epidemiology and bio-statistics. Considerations related to random variation, exposure, outcome, potential effect measure modification and confounding are central

here and call for knowledge on universal and typical aspects. A knowledge, which is understood independently of the context – a context-independent knowledge.

- The complexity of the context on the individual level of the patient perspective request detailed in-depth descriptions of how life with AF is lived. Life with AF impacts on aspects of daily life, family life and work life, and self-reported health. Knowledge on humans' lived experience as well as uniqueness of self-reported health for the individual patient lies within the hermeneutical-phenomenological tradition (Van Manen 2014). According to van Manen (Van Manen 2014), much of phenomenology has hermeneutical (interpretive) elements, but not all hermeneutics include phenomenology (Van Manen 2014, p.26). The phenomenological reduction is central, and includes willingness for bracketing pre-understanding (past knowledge). Thereby, a request for an open attitude towards how life phenomena are expressed in a real-world context - like life is lived through. A phenomenological attitude is therefore important for accessing knowledge on the uniqueness related to lived experience as well as self-reported health. Central concepts within this tradition are 'phenomenon', 'life-world', 'lived-experiences' and likewise 'pre-understanding' (Norlyk & Harder 2010; Van Manen 2014; Gadamer 2007). Knowledge on lived experience calls for context-dependent knowledge, because it aims to provide understanding and insight into a human life, as lived through. For the researcher, this understanding and insight request an open attitude towards human pre-understanding. This can be facilitated through daily activities, human actions and description of own situation. Acknowledgement of the richness, complexity and nuances in lived experience is important (Van Manen 2014, pp.39–40). Researcher participation, pre-understanding, interpretation and in-depth descriptions are therefore essential.

Phronetic science with respect and acknowledgement of potentially conflicting research traditions is therefore important for embracing the full story about the patient

perspective. There is no such ‘universal’ textbook covering considerations for a case study design (Yin 2014). Methodological considerations in a specific case study therefore call for sufficient knowledge and a detailed description of the case of interest. A research design of a case study is thus not just a work plan, but also an outline of case study questions, propositions, description of the case of interest and units of analysis, linking of data to the questions and propositions and describing criteria for interpretation of study results and findings. Design is thereby essential for a case study, and will be further elaborated in the following sections of this chapter.

5.2. CASE OF INTEREST

The case of interest in this case study is the patient perspective of the journey of living with AF. In order to clarify the case of interest, the description contains a definition and characteristics of an extreme, critical and longitudinal case (Yin 2014, p.51; Flyvbjerg 1991, pp.149–153; Flyvbjerg 2001, pp.77–80). In this outline of the case of interest, a common case is likewise described to clarify the extreme, critical and longitudinal criteria, with its contrasts. At the end of this section, I will present Peter. Peter’s one-year journey is an example of an extreme, critical, and longitudinal case, and is one of the data sources of this case study, fully elaborated in Paper 3.

Both from the World Health Organisation (2006), and related to primary care (Davies 2015) there is an international interest in the patients’ perspective on experience of the journey in relation to quality of care. In a Danish context, a connected journey is one of the goals of high quality of care (Hansen & Kruckow 2008). Also exemplified from a study on Danish patients living with an autoimmune condition (Jansbøl 2014). The goal is referred to as a connected journey in the healthcare sector, in the hospital, and community care as well as in general practice. In this case study, significant events in daily life, family life and work life of the unique human being together with self-reported health define the patient perspective of the journey of living with a disease. Related to AF, humans are classified as patients in the healthcare system. The journey therefore specifically involves contacts with general practice, the hospital and

community care, and acknowledges the usage of diagnoses to describe and characterise health-related conditions. Knowledge on the patient perspective of a specific patient journey can thereby inform about both typical and unique human aspects related to the journey. Particularly, lived experience related to daily life, family life and work life contribute with the uniqueness of the individual patient, and self-reported health with knowledge on typical patterns related to this uniqueness. Quality of life is a central concept for the case study design, because it is commonly used in the scientific research context. In order to access knowledge on typical patterns and magnitude related to the patient perspective of living with AF, standardised health status assessment tools are also of interest for this case study. Both generic e.g. Short Form 36 (SF-36) (Maruish 2011) and disease-specific e.g. Atrial Fibrillation Effect on QualiTy-of-life (AFEQT) or the disease-specific health-related quality of life questionnaire for patients with AF (AF-QOL) (Arribas et al. 2010; Spertus et al. 2011) assessment tools are of interest in order to express patients self-reported health. The patient's lived experience of his own situation as a whole, quality of life and self-reported health status, both on the individual and on the population-based level, related to a hospital and community setting, is thereby considered the case of interest.

5.2.1. AN EXTREME, CRITICAL AND LONGITUDINAL CASE

Based on a literature review and experience from clinical practice, an extreme, critical and longitudinal case (Yin 2014, p.51; Flyvbjerg 1991, pp.149–153; Flyvbjerg 2001, pp.77–80) is here defined as:

- Lived experience and self-reported health status in the one-year journey of a younger, physically active, employed man recently diagnosed with symptomatic lone paroxysmal AF, living with his family.

In contrast, a common case is considered the journey of an older patient, with AF being one among others diseases. In a common case, AF will probably be the smallest concern compared with other more serious and potentially immediately life-

threatening comorbidities. The extreme and critical aspect has particularly been selected due to its potential for a logical deduction on unpredictability, concerns, and burdens influence on management of daily life, family life and work life. Thereby, the criteria of an extreme and critical case are based on providing the best-expected conditions for focusing on the impact from AF. A journey of a patient with paroxysmal or persistent, lone and symptomatic AF and without effect from medical treatment was selected in order to elaborate on the patient journey related to both hospital and the community. This type of patient will typically be offered a radio frequency ablation (Camm et al. 2012) and is likely to be offered oral anti-coagulant treatment resulting in frequent check-ups in general practice. Symptomatic AF is expected to trigger and aggravate psychological distress (McCabe & Barnason 2012). The European Heart Rhythm Association Score (EHRA) express symptoms from AF (Camm et al. 2010, p.10). Symptomatic AF is defined by: EHRA class III – ‘severe symptoms, normal daily activity affected’ and EHRA class IV – ‘disabling symptoms, normal daily activity discontinued’.

Despite the onset of AF in men being earlier and more frequent than in women (Rahman et al. 2014; Camm et al. 2012; Feinberg et al. 1995; Rich 2009), a man was selected to represent an extreme and critical case. This selection was due to clinical experience of younger physical active men (e.g. triathletes, marathon runners or long endurance sport athletes) often facing a special struggle related to life with a symptomatic AF. The age of 50-65 years is considered due to lone AF being most frequent among younger men (Frost 2009; Jahangir et al. 2007), and to provide the opportunity of relating results from generic health status available from a larger population in the Danish Diet, Cancer and Health Study (is further elaborated in Paper 2). Living with a partner is important to illuminate potential impact from AF on family life. Status as employed is a requirement to be able to elaborate aspects related to work life. Being physically active and experiencing limitation in daily activities due to AF may be a special struggle. Therefore, being both passionate about physical activity, and actually physically active, is expected to characterise an extreme and critical case. The criterion of a longitudinal case was selected to follow the patient perspective over

time. A one-year journey was selected to allow sufficient time for getting involved as a researcher to collect data on lived experience from daily life, family life and work life. Moreover, this was considered an appropriate time for evaluating the outcome after radio frequency ablation and a likely change in self-reported health.

5.2.2. PRESENTATION OF PETER

Peter is a 54-year-old man who lives with his wife in a flat. Peter enjoys running and biking with the local biking club and with his son. Due to breathlessness, Peter is, however, often, and without any forewarning, forced to stop a given physical activity and is therefore not always able to complete the weekly exercises he used to do. Additionally, returning home from work Peter has trouble climbing the stairs to his flat on the 2nd floor. For the last 39 years, Peter has managed a full-time job as machine operator.

In 2006, Peter was referred to the emergency room due to a tendency to faint and breathlessness during physical activity. Eventually, Peter was discharged without any follow-up. Over the years, Peter received medication for asthma, without any notable effect. In spring 2011, and due to shortness of breath during physical activity, Peter consulted his general practitioner and was referred to a cardiologist. The cardiologist found signs of paroxysmal AF, but no structural heart disease. Peter was recommended to contact his general practitioner to initiate treatment with beta blockers. The treatment with beta blockers was, however, terminated due to an episode of fainting during physical exercise. In August 2013, Peter experienced significant physical limitations while biking and running and dizziness related to his work. Therefore, due to progressing breathlessness, palpitations, and episodes of dizziness, Peter was again referred to the cardiologist. At the cardiologist, numerous episodes of rapid AF and low frequency heart rhythm, related to spontaneous conversions to sinus rhythm, combined with episodes of nearly passing out, were documented. Therefore, Peter was told that further treatment required hospital admission for medication or radio frequency ablation. This is the point when Peter

was recruited for the single-case study, reported in Paper 3. Further details and descriptions of Peter's one-year patient journey will be presented in Chapter 6. For elaborating on the case of interest, the case study is based on the data sources listed below.

5.3. DATA SOURCES

Data sources for this case study consist of:

- scientific research papers using the concept of quality of life in the context of patients living with AF
- standardised questionnaires assessing generic self-reported health status in life with and without AF in a Danish population and for Peter
- standardised, disease-specific, self-reported health status questionnaires for Peter in his one-year journey
- field notes from participant observations from Peter's one-year patient journey based across organisational sector boundaries, in the hospital and in general practice
- a reflective diary written in connection with my work as a researcher collecting data, emphasising the importance of my role and position
- transcripts of conversations between Peter and healthcare professionals in his journey
- transcripts of interviews conducted during home visits, involving the perspectives of the impact of AF on daily life, family life and work life for Peter and his significant others
- the medical record relating to Peter's one-year journey from both hospital and general practice
- written information and letters Peter received from the hospital during his journey.

The data sources are the base of the three papers and will be presented in details in Chapter 6. Considerations related to the study outline and connections between the three papers are illuminated in the section below.

5.4. STUDY OUTLINE

The dissertation is based on a case outlined in three studies and three research questions. The study is reported in three papers.

Paper 1 – Title: *Quality of life – exemplified through patients living with atrial fibrillation.*

- Elaborating on inconsistent and contradictory contents and the dynamics related to the applicability of the concept of quality of life.

Paper 2 – Title: *Associations between the diagnosis of atrial fibrillation and aspects of health status. A Danish cross-sectional study.*

- Investigating the association between being diagnosed with AF and aspects of self-reported health status.

Paper 3 – Title: *A year in the life of a person recently diagnosed with atrial fibrillation in Denmark.*

- Illuminating the individual level of the patient perspective of the journey with AF in Peter's one-year patient journey, related to daily life, family life and work life and across organisational sector boundaries in the healthcare system.

The case study thereby involves three embedded units of analysis.

Being embedded or holistic is not a question of number of participants, but a question of units of analysis, and how these are integrated in the case study (Yin 2014, p.50). An embedded design is appropriate for complex phenomena where sub-units exist in the context (Yin 2014, p.55). Lived experience, quality of life and self-reported health are considered sub-units for the patient perspective. These sub-units are all relevant for telling the story of the patient perspective, related to complexity and magnitude of the context. Investigating lived experience is essential for elaborating on the complexity of the context of the patient perspective. Surveys, on the other hand, are relevant in order to elaborate on the magnitude of the case, but limited in order to investigate the context and complexity (Yin 2014, p.16). The patient perspective involves human behavioural aspects. Therefore, as a researcher, I cannot a priori know about and control the patient's expressions of unique and typical human patterns related to their lived experience and self-reported health. This issue requires a flexibility and openness towards the case of interest. The literature review in Chapter 2 constitutes the basic grounding for formulating a study protocol. The study protocol (Yin 2014, pp.45–49) has been an important tool and guide for mapping the flexible inquiry, and for strengthening reliability and readers' ability to follow the study throughout the process of performing the case study.

The connections between the study context, the three papers(three embedded units of analysis) and the discussion section are displayed in Figure 1.

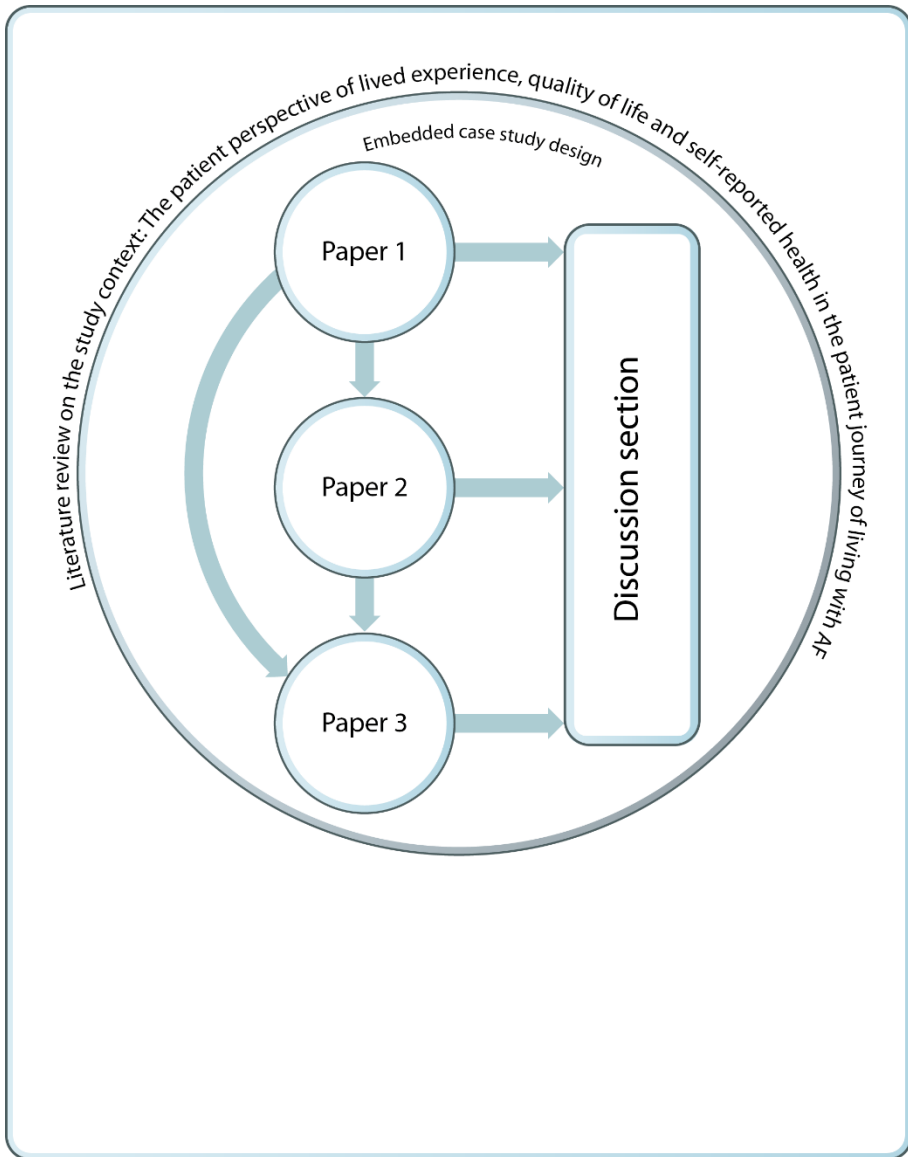


Figure 1. Connection between study context, papers and their contribution to the discussion section.

As illustrated in Figure 1, all three papers are positioned in the study context of the patient perspective of living with AF and involve aspects of this context. The three

papers are performed and reported separately, but results from Paper 1 are integrated in Paper 2 and Paper 3, and results from Paper 2 are integrated in Paper 3. Furthermore, the results from the three specific papers are integrated in Chapter 8 (the discussion section) in order to elaborate on the case of interest.

Together with the literature review in Chapter 2, Paper 1 strengthens the theoretical base of the case study and the study protocol, as it elaborates on the diversity of the concept of quality of life, how it is applied in the context of patients living with AF, and debates potential consequences of inconsistent use of various labels for the concept.

Based on the World Health Organisation definition (WHO 1997), the results in Paper 1 characterise the concept of quality of life as complex, multidimensional, context-dependent and dynamic. These features of the concept require definition and argumentation, when the concept is applied in a scientific context. The World Health Organisation's definition is referred to in Paper 2 and Paper 3, in order to be specific on a definition. Reflections from Chapter 2 and Paper 1 thereby contribute to the design of Paper 2 and Paper 3.

Paper 2 followed Paper 1 and the literature review in order to assess the association between being diagnosed with AF and self-reported health in a study with strong statistical power. Paper 2 is thus an important contribution to the association between being diagnosed with AF and self-reported health status. However, the results from Paper 2 have to be reflected in a dialogue on the individual patient's specific situation as a whole in order to be applied in a clinical practice setting.

Both Paper 2 and Paper 3 deal with aspects of the concept expressed in self-reported health status. Paper 2 related to the association between AF and self-reported health based on a generic questionnaire, on a population based level. Paper 3 on the individual level, with report of both lived experience and self-reported health, from both a generic and two disease-specific questionnaires. As emphasised by the results from the literature review and Paper 1, a combination of qualitative and quantitative

data is needed in order to tell the story of the patient perspective and thereby access information on the patient perspective. Paper 3 provided knowledge on the individual patient's perspective from a one-year journey by combining qualitative and quantitative data sources. This is likewise an important contribution to the case study.

Symptom burden and time dimension for self-reported health are crucial for the association between AF and self-reported health. Covering the impact from symptom and time is not possible in Paper 2, because data on self-reported health is reported only at one point in time, and from a generic tool (SF-36 version 2). Thereby, not providing information on specific symptoms and conditions related to AF. Paper 3, however, contributes with in-depth and longitudinal descriptions of lived experience of quality of life related to daily life, family life and work life, and self-reported health in the one-year journey. Paper 3 illuminates the possible impact of symptoms on the association between AF and self-reported health status on the individual level. SF-

SF-36v2 is included in both Paper 2 and Paper 3 to contribute information on self-reported health. SF-36v2 is applied on a population based level at one point in time in Paper 2, and on an individual level over time in Paper 3. Both SF-36v2 (Maruish 2011), AFEQT (Spertus et al. 2011) and AF-QOL (Badia et al. 2007) can be applied on both levels. Even though, use of questionnaires in Paper 3 can likely elaborate on some of the unanswered aspects of the results of significant differences in physical component scores and the surprising result of no significant difference in mental component score of health status in Paper 2. AFEQT (Spertus et al. 2011) is reported to catch Peter's physical limitations in daily life at the six-month stage better than AF-QOL (Badia et al. 2007; Arribas et al. 2010) and SF-36v2 (Maruish 2011). AF-QOL catches the impact on 'sexual activity', which is not specifically covered in AFEQT and SF-36v2. The scale of 'daily activities' in AFEQT is found to be more strongly associated with Peter's physical limitation from AF than the scale of 'symptoms'. Additionally, Peter's struggle recognising bodily reactions is found to be connected to this issue. Involving all three questionnaires, Paper 3 is thus likely to clarify the connection between the results of the questionnaires and relate information on self-reported health status to descriptions of lived experience.

The researcher's pre-understanding related to the study outline has been important. Outlining and defining a research question or a hypothesis, designing and planning a study, collecting, analysing, interpreting and discussing data, and describing implications of the study results. In particular related to data collection for Paper 3, where I followed Peter in a close relation, on his one-year journey. I experienced being challenged on my reflection and pre-understanding, and experienced how reflection-in-action was essential for acting in the situation with Peter. Therefore, it is necessary to describe my pre-understanding and considerations in my role as a researcher, and furthermore provide descriptions of six central examples.

5.5. ROLE OF THE RESEARCHER

Conducting the research for this dissertation has been an exciting, but also challenging journey for me. As humans we experience the world, and thereby also the scientific research process, as we live through it (Van Manen 2014; Merleau-Ponty 1962). My lived experience from this process is therefore the basis for my pre-understanding. With pre-understanding being the basis for the reflective process of understanding (Gadamer 2007), systematic reflection, awareness of my role and pre-understanding as researcher and a registered nurse have been important throughout my journey of conducting the case study. This awareness has been facilitated by writing a reflective diary and continuously discussing progress with my supervisors and my colleagues, both in research and clinical practice. Reflection and learning are a continuous process of challenging one's own pre-understanding in order to widen one's horizon. Horizon fusion with another understanding different from one's pre-understanding is only possible by this challenge and awareness towards one's own pre-understanding (Gadamer 2007).

5.5.1. THE PROCESS OF THE HERMENEUTICAL CIRCLE

In the case of interest, I investigated a familiar field, organisation, and geographical location. It was therefore particularly important for me to clarify my pre-understanding before starting the study. Therefore, prior to writing my study protocol, I investigated my pre-understanding by undergoing an interview performed by an

interviewing trained colleague. My main supervisor observed the interview, and subsequently I formulated a statement of my pre-understanding. The interview facilitated this process, because the questions from my colleague made me reflect on my understanding of the case of interest. Having my supervisor observe the interview was important for our continuously reflective dialogue, which has been helpful throughout the study. Being there listening to the interview strengthened her ability to pose elaborating questions, which likewise facilitated awareness of my pre-understanding. The statement of my pre-understanding was helpful through data collection and data analysis. It was likewise useful in conversations with my co-supervisors. The following accounts for the central content of this statement.

As a newly educated nurse in an acute cardiac department, I was taught that patients admitted due to AF were considered non-complex. Even when they were readmitted, awaiting a direct current cardioversion due to relapse of AF, they were not necessarily in an immediate life-threatening condition. Generally, we provided these patients with a chair in the hallway of the bed unit, and they could wait for hours before receiving the needed intervention, medication or information. Comparing with patients suffering from cardiac arrest and immediate life threatening cardiac and arrhythmic conditions like ventricular tachycardia or hypertensive in-compensation, this was due to being in the lowest immediate risk of death. However, over the years (7 years of work as a nurse) based on conversations with patients admitted due to AF and focus group interviews with patients on their experience of readmission (Høgh et al. 2010), my understanding changed. I became aware of how the patients experienced the condition with relapse of AF as terrifying and the time in the hospital as a struggle and waste of time. Furthermore, how they experienced being marginalised, overlooked and confused by receiving conflicting information provided by a variety of healthcare professionals.

The rest of this section covers reflections related to the reflective process based on my pre-understanding in connection to my journey of performing the three papers.

5.5.1.1 Reflections on Paper 1

I have continuously reflected on the complexity of the concept of quality of life and the use of the concept as a measurement. How can one person's quality of life be 'better' than for another person, measured by a standardised health assessment tool? Moreover, how can it be meaningful to assess quality of life, from a standardised health status assessment tool? This wondering emerged and increased by reading scientific research papers on the populations of patients with AF. From reviewing the literature I realised that my wondering was already debated (Gill & Feinstein 1994). Despite discussions in the literature, my wondering about the importance of definitions and arguments applied in a scientific context remained relevant, because no study to date has exemplified and debated this issue and its consequences within the context of patients living with AF. Despite my doubt, the concept of quality of life was applied as a measurement in the scientific context. Along the process of working on the dissertation, I became aware of validity, reliability, strengths and limitations of assessment tools and within different scientific research traditions. A conscious and reflective attitude and openness towards specific context, editorial limitations and conditions for specific scientific papers was important in order to investigate on my wondering. In this process, I used my supervisors and colleagues for cooperating discussions. My wondering and pre-understanding thereby lead to designing Paper 1.

5.5.1.2 Reflections on Paper 2

Outlining, designing and performing Paper 2 has been a special journey for me, because I had limited experience in epidemiology and bio-statistics a priori. The terminology, methods and principles for this area were new for me. At the beginning, I really felt like being in a new place. Despite this feeling, I was curious as to whether and how it made sense to measure quality of life. Challenging my doubt and curiosity, I performed the research for Paper 2 aiming to assess the association between the diagnosis of AF and self-reported health status, based on reports of the Danish SF-36v2, from a follow-up in the Danish Diet, Cancer and Health Study (Tjønneland et al. 2007). Paper 2 had a large sample size with 873 participants with AF, and thereby a strong statistical power was expected to bridge some of the gap located in the

existing literature, on studies allowing relevant stratification and adjustment related to the heterogenic population and to relate estimates to a general population. By getting familiar with the process of designing an epidemiological study using a statistical model with corresponding assumptions, the process of working on Paper 2, expanded my horizon. By reading, trying and receiving qualified supervision, it has been an interesting learning process for me. I have learned about the work needed to be done before you can push the button in the statistical software program to get the results. The scientific work lies in formulating the research question and interpreting the results, rather than producing the numbers *per se*. I have learned about the importance of skills, knowledge and awareness related to choosing an appropriate design with specific assumptions and choices for modelling the study and related to interpretation of results. I have been humbled throughout this journey of learning. Moreover, I have faced the struggles interpreting and drawing perspectives toward the study results, not only as a statistically significant result but also as related to clinical importance. My pre-understanding has thereby been essential throughout this process.

5.5.1.3 Reflections on Paper 3

When collecting data for Paper 3, I was engaged in my relation with Peter, his significant others and healthcare professionals involved in his one-year journey. I played a significant role as a researcher, a registered nurse and a woman. Without my engagement, the extent of detailed data collection would not have been possible. Working within the tradition with a hermeneutical-phenomenological inspired approach was familiar for me. Thus, I realised how unique and flexible the process of data collection in an extreme, critical and longitudinal case can be. Unique, because every process of data collection depends on the case of interest. Flexible, because the case of interest cannot be fully predicted *a priori* but develops over time, leading to constant requests for reflection. Despite my familiarity with the research tradition, I discovered how reflection, wondering, responsibility, openness and awareness are constantly required in order to enter a research field, collecting data and ending a study. The process of data collection and my relation to Peter were like a constant balancing between human closeness and preserving an analytical distance. The text

below presents a description of six detailed examples of my role as a researcher and a nurse related to this balance. The examples are based on reflections in my research diary and conversations with my supervisors, and are central because these situations especially requested reflection-in-action and action. Furthermore, these examples kept coming back to me in the process of the qualitative data analysis (Giorgi 1997; Kvale & Brinkmann 2009b).

Example no. 1. -‘This is my bodyguard’

It came as a surprise to me when Peter introduced me saying “This is my bodyguard”, at the first visit to the outpatient clinic in the hospital and in his general practice. This statement made me reflect on whether I had become too private with Peter. Thus, I discovered that this label might mean something crucial for him, like a protector, an indication of Peter feeling safe when I was around. I had a feeling of discomfort, especially in the beginning, when I needed to visit and engage with Peter’s life outside the direct healthcare environment. I felt being outside my own comfort zone. In contrast to my engagement, I experienced the need for preserving distance during the process of data collection. Managing the balance between human closeness and preserving an analytical distance required a constantly reflective process. It took some time, reflection and courage for me to realise, that when Peter continued to use the label ‘bodyguard’ and tended to tease me with a smile on his lips, it was a sign of him feeling comfortable and confident with having me around. It was surprisingly easy to gain Peter’s confidence, include him in the study, and get access to the healthcare setting – the hospital and the general practice. In contrast, it was harder to access and talk with Peter’s family and colleagues. After some time and conversations, he was comfortable having me meet with his family at home. This access developed when he invited me to meet with his colleagues during an evening shift at the six-month stage of the study. Peter also expressed his enjoyment of having me around, during the 5 km run at the 10-month stage, when he invited me for a barbecue with him and his colleagues after the run. Thereby, I gained access to talk with his colleagues in relaxed and informal circumstances.

Example no. 2. - ‘Why don’t you just stop running?’

From the first home visit, Peter kept repeating the expression, ‘But why don’t you just stop running and start walking instead?’ His general practitioner had responded with this statement when he complained about his unpredictable physical limitations associated with running. To Peter running was an indicator of quality of life. Even though he never told his doctor about the impact this statement had on him, he was disappointed about this response. As time went on, I occasionally talked with Peter’s general practitioner in the waiting room while waiting for Peter to arrive. I asked what the general practitioner knew about AF, and it turned out that he suffered from AF himself. He had an ablation once, but as he explained that accounting for the risk of complications related to the operation, he did not have the courage to have another one, even though he occasionally felt his AF. He said that he did not consider AF critical compared with other diseases, which he became familiar with in his daily work as a general practitioner. He had stopped running and started walking instead. I faced an ethical challenge about whether to tell Peter about this and potentially help decrease his disappointment. During the last home visit, I told Peter about this. Peter was surprised, but it then made sense to him why the doctor had asked why he could not just walk instead of running.

Example no. 3. - An admission vs. an out-patient examination

During the second home visit when I was interviewing Peter’s wife and son, Peter returned home from the gym. Peter presented me with two letters from the hospital related to his upcoming radio frequency ablation: one from the department of cardiology, and one from the department of radiology. From reading these letters, it became clear that Peter had missed a significant blood sample (s-creatinine) prior to the planned Computed Axial Tomography (CAT-scan), in the department of radiology. Peter explained that he understood that the blood sample only needed to be done three to six days prior to admission for radio frequency ablation in the hospital, and not prior to the outpatient CAT-scan. As Peter received the two letters on the same day, he had mixed them up. From Peter’s perspective, admission included staying over-night. Peter had misunderstood the different requirements for an admission and

an outpatient examination. I encouraged Peter to contact the hospital to organise when he could have the blood sample done, prior to the CAT-scan. Peter asked me to contact the hospital for him, but I kept encouraging him to do it himself. Peter then asked his son to do it for him, which he did. Peter's son arranged for getting the blood sample taken in the morning of the planned CAT-scan. The fact that I drew his attention to the missing blood sample may potentially have prevented a cancelation or extension of his radio frequency ablation. However, later on, during his admission, it turned out that Peter was double booked for the CAT-scan. Apart from the CAT-scan mentioned in the letter from the department of radiology, he was scheduled for an additional CAT-scan on the day of pre-examination prior to admission for radio frequency ablation. So potentially, Peter might have discovered and solved this misunderstanding, without my interference. Nevertheless, ethically I could not neglect to react in this specific situation in Peter's living room that Friday afternoon.

Example no. 4. - Engaging to achieve completeness of data

From both an ethical and methodological standpoint, completeness of data was important for me. Ethical, to show engagement in Peter's one-year journey and methodological to achieve insight into all significant events in his journey. It was, however, a challenge to balance how much private information I should give to Peter. In connection with the fourth visit to the general practice nurse, I experienced a conflict with the timing of a funeral for a close family member, making attendance at the scheduled visit difficult. For me it was challenging to make the decision whether to attend the funeral or Peter's visit. I was afraid that telling Peter the real reason would give too much attention to me as a private person. Thus, after reflections and conversations with my supervisors, I chose to tell Peter about the real reason for not participating in the visit. Peter was supportive, and we agreed that he should go to the nurse by himself, and then I would call him on the phone after the funeral. Additionally, during annual holidays and vacations Peter needed weekly assessments of his International Normalised Ratio (INR) as an important part of his oral anticoagulant treatment. It was much easier for me to make the choice of terminating my vacation a few days earlier than planned to be able to participate in the visit. Thus,

I found the seriousness of the private issues was important for the challenge of making a decision and achieving completeness of data.

Example no. 5. - Unexpected challenge of recording conversations

My intention was to record all the conversations Peter had with healthcare professionals in hospital and general practice to ensure to capture most possible details of the conversations. However, it was difficult to collect written consent forms from all healthcare professionals prior to their conversations with Peter. To my surprise, it turned out that only a few healthcare professionals consented to recorded conversations. I encountered significant resistance from a former colleague to recording conversations. The reaction related to the applicability of a study with one participant. However, after discussing the methodology, the healthcare professional agreed to participate. Recording of conversations did not seem to affect the general practice nurse where Peter had 36 visits. Time and regularity thereby appear to have an impact on the healthcare professionals' attitude. After this episode, I started to reflect upon why it was important to record all the conversations related to admission. I realised that my purpose in wanting to record all conversations most likely reflected my insecurity as a novice researcher collecting data for the case study. Supported by my supervisors and descriptions from the case study literature suggesting not to record conversations if the participants were uncomfortable with the recording procedure, I challenged my own insecurity and chose not to record conversations related to Peter's second admission. Instead I was present and aware and recorded notes in a small notebook and then went back home to type up my field notes. Not recording Peter's conversations with healthcare professionals resulted in them talking more naturally and freely, thereby providing a feeling of a much more natural patient journey for Peter.

Example no. 6. - Ending data collection

Ending data collection and the relationship with Peter was one of my concerns even before recruiting him. I was aware that even though the study ended, Peter's life would not end, and I felt an ethical responsibility to ensure that he had the tools and support

to be able to manage and continue his life with AF without me. Peter was not used to involving his wife in the visits to the hospital and his general practitioner. I was therefore worried whether I would interfere in the relationship between Peter and his wife by participating in all Peter's visits to hospital and general practice. I therefore chose to involve Peter's wife where possible. It felt natural to involve her as she came home during the first home visit and participated in the conversation. Towards the end of the study, Peter started to include his significant others in his healthcare by telling his wife and son that they were the ones who had to take care of him when the data collection ended. A natural point for ending the study occurred, as I would go abroad for a research stay shortly after ending the data collection. I had told Peter and his family about this from the beginning.

In summary, my role as a researcher, a registered nurse and a human being made reflection on my pre-understanding and understanding along working with the dissertation and all three papers essential.

CHAPTER 6. PAPERS

In order to describe how the three units of analysis in the three papers contribute to elaborate on the case of interest and existing knowledge, methods, main results, conclusions and contribution will be presented in this chapter. As an overview, aims, designs and data sources of the three papers are displayed in Table 3.

Table 3. List of papers (1-3) including aims, data sources and designs.

	Aim	Design	Data source
Paper 1	To investigate how the concept of quality of life is defined and what arguments are given for using the concept in scientific research papers on patients living with AF.	Text analysis.	53 scientific research papers based on a systematic literature search in CINAHL, PubMed, Cochrane Library and Bibliotek.dk.
Paper 2	<p>To investigate the association between being diagnosed with AF and self-reported health status.</p> <p>Hypotheses: Participants in the Diet, Cancer and Health cohort with the diagnosis of AF exhibit a lower self-reported health status than the remaining participants in the cohort. Gender and age are expected to modify the association. The association is expected to be stronger among women than among men and to be weaker in older compared to younger age groups. Being diagnosed with AF is expected to be more strongly associated with health status in a younger than in an older person, due to the higher comorbidity with age.</p>	Epidemiological observational cross-sectional study.	SF-36v2 questionnaires from the Danish Diet, Cancer and Health study.

Paper 3	To explore in-depth descriptions of lived experience, quality of life and self-reported health in a one-year journey of being recently diagnosed with AF.	Single case study based on Peter's one-year patient journey of being diagnosed with symptomatic AF. Peter's journey is considered an extreme, critical and longitudinal case.	Participant observations. Reflections and descriptions from a reflective diary. Transcripts of conversations. Transcripts of interviews. Medical record Written information and letters. Questionnaires.
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6.1. PAPER 1

6.1.1. METHOD

The paper is a text analysis, focusing on definitions and argumentation in scientific research papers in the context of patients living with AF, applying the concept of quality of life. The analysis is based on two research questions:

- How is the concept of quality of life defined?
- What reasons are given for using the concept of quality of life?

In particular, interest is on identifying definitions of and arguments for the concept of quality of life related to the content of scientific papers, and not only the content by it-self. The context of argumentation and definitions in scientific research papers is therefore of interest. A strength related to text analysis is identification of contradictory content in texts and thereby elaboration on the context of a given text (Koch & Vallgård 2007; Silverman 2006; Becker Jensen 2011). Focusing on how the concept is applied and understood and not only the content of the text by it-self, the analysis is carried out based on Danish scholar Leif Becker Jensen's suggestions for text analysis. His suggestions are in particular useful for focusing on context

related to definitions and argumentations in scientific texts, because both the *text close analysis level*, the *communicative level* and the *societal level* are important, and because he emphasis argumentation in text, by elaborating on for example tricks of arguments and societal agreements prioritised (Becker Jensen 2011). The communicative and the societal level are important for this paper, because they facilitate understanding of the context related to the concept of quality of life, and not only the content of the text. The method thereby embraces potential influence from conflicting scientific research traditions.

According to Becker Jensen, there is “no analytical approach fits all” for text analysis. Descriptions of the process of building the research question and argumentation for selecting the analytical approach are therefore essential for the analysis. Text analysis is a process of posing a set of questions, elaborating on a research question, and providing a well-documented argumentation of this interpretation. Accordingly, text analysis can be inspired by more than one analysis strategy (Becker Jensen 2011, p.37). The 13 most applied analysis strategies are; Content analysis, Critical source analysis, Framing analysis, Genre analysis, Argumentation analysis, Style analysis, Narrative analysis, Readability analysis, Improvements analysis, Origin analysis, Discourse analysis, Comparative analysis and Quantitative/qualitative analysis (Becker Jensen 2011, pp.37–44). Particularly, argumentation analysis is of interest for this study.

In order to formulate research questions for this paper, the study started with a literature review on the development of the concept of quality of life in general. This literature review lead to a description of inconsistent use of labels, and quality of life being aligned with health status and health-related quality of life. The analysis is hereby theory guided. Moreover, it showed that there is no consensus on a clear definition of the concept. Hence, we formulated the research questions for the paper. According to Becker Jensen, all texts are open to interpretation. Depending on type, texts can be positioned on the continuum between being completely open and being closed towards interpretation. Scientific texts, as included in this study, are often positioned in the ‘closed’ end of the continuum, because of the requirements for clear

definitions, documentations and explicit presentation of theoretical references (Becker Jensen 2011, p.25). This implies taking the context of the specific text into account, and therefore we also expected to be able to locate definitions of the concept and an argumentation for applying it. The data sources therefore consist of 53 scientific papers selected based on a systematic literature search in CINAHL, PubMed, The Danish National Library Database, and the Cochrane Library on ‘atrial fibrillation’ and ‘quality of life’. Specific details from this search are displayed in Figure 1 in the paper.

Inclusion criteria:

- patients with AF
- the concept of quality of life included
- scientific research papers.

Exclusion criteria:

- treatment-specific texts
- patients with pacemakers
- editorial comments
- children (under 18 years).

Text analysis as suggested by Becker Jensen is grounded within the hermeneutical research tradition, described by the German philosopher and Professor Hans-Georg Gadamer. Understanding and interpretation within this tradition concerns working in the hermeneutical circle. Confrontation with one’s own pre-understanding can lead to the opportunity of achieving a horizon fusion, an expanded understanding (Gadamer 2007). Moving from a common-sense understanding of a text to the analytical level is an active process, requesting openness, curiosity, critical reflection and awareness of own pre-understanding. Furthermore, related to text analysis using a given set of categories, Silverman adds a risk of falling into a ‘grid’ with the non-coded material in risk of being overlooked, and thereby with findings not providing the context of the analysis and material (Silverman 2006). We, as a team of co-authors, used each other

for undertaking the analysis of the scientific research papers, keeping ourselves and each other in mind to be open and curious to the texts and the process of analysis. By continuously questioning each other, challenging one another's understanding, and engaging in reflections in the process of analysis, this teamwork is considered a strength.

6.1.2. MAIN RESULTS

We located three categories of definitions and five categories of arguments for using the concept (also displayed in Figure 2 in the paper).

Three definitions:

- the World Health Organisation's definition (5 texts)
- quality of life assessable, as a parameter (29 texts)
- quality of life is a subjective and multidimensional concept (6 texts).

Five arguments:

- multidimensional aspects included in the arguments (13 texts)
- using SF-36, because it is the most valid and used tool (8 texts)
- important for gaining insight into the patients perspective (7 texts)
- need for a new tool (5 texts)
- importance of qualitative aspects of the concept (1 text).

In 13 of the 53 scientific papers, no definition of the concept of quality of life is provided, and in 19 of the papers, arguments for using the concept of quality of life are missing. The World Health Organisation defines the concept of quality of life as a subjective and multidimensional concept, and thereby not an obviously assessable parameter. Likewise, ability to gain insight into the patient perspective and qualitative aspects of the concept by using a qualitative approach is found to be an important argument for using the concept. In contrast to this understanding of the concept, existence of an implicit societal agreement on the concept being aligned with an assessable parameter in the scientific context of patients' perspective of quality of life is suggested.

6.1.3. CONCLUSION

Definition of and arguments for applying the concept of quality of life are important for the validity of a scientific research paper. The diverse concept is aligned with assessable parameters. With missing arguments and definitions, the meaning of the concept is suspected to be taken for granted. This might be a threat to the valuable subjective variation and content embedded in the concept. In the scientific context of patients living with AF, it is therefore crucial to request definitions of and arguments for the concept of quality of life, and to challenge the suspected implicit societal agreement.

6.1.4. CONTRIBUTION

Paper 1 elaborates on inconsistent use of labels for the concept of quality of life in the scientific research context of patients living with AF. By elaborating on the context of scientific texts concerning quality of life within patients living with AF, the paper is an important contribution to the theoretical base for the case study (Yin 2014) – this dissertation.

The results from Paper 1 are in line with what has earlier been described by Carr and Higginson (2001) related to questioning if quality of life measures are patient-centred. Likewise, related to inconsistent use of labels used for the concept, described by Moons (2004). Inconsistent use of labels and lack of discussion of the validity and sensitivity of a given questionnaire to assess aspects of quality of life can lead to risk of misinterpretation of study results. In relation to the context of patients living with AF, it is problematic, because inconsistent use of the concept can lead to loss of valuable information on the patients' subjective lived experience, and the patients being reduced to the disease of AF. Furthermore, if the full patient perspective is considered assessable from a standardised questionnaire, the patient perspective of what is important in the journey of living with AF is potentially at risk of being aligned with the perspective of the healthcare professional, researchers, or the developers of a questionnaire. Inconsistent use of labels for the concept can lead to the meaning of the concept being taken for granted, and thereby development of an implicit societal

agreement. As emphasised in this paper, we found signs of such an implicit societal agreement. Such an agreement is problematic and complex, due to being implicit and thereby difficult for the people included in the society (scientific research society) to recognise. Moreover, such agreement might lead to lack of a direct demand from the society for defining and arguing for the concept. Based on Toulmin's model of arguments (1958), argument tricks e.g. expert and authority arguments, located from the text analysis, can serve as a warrant in the chain of argumentation without a demand for relevant documentation (Becker Jensen 2011, pp.81–82). Within an academic scientific context, definitions and reflection on concepts used is central to the transparency and rigour of a study (Eriksson 2010; Chinn & Kramer 2007; Wahl & Hanestad 2004). This is especially important for applying the diverse concept of quality of life. Reflection on one's pre-understanding is therefore important in order to challenge this agreement. The agreement, being implicit, challenging and making the societal agreement explicit, therefore calls for a special openness and awareness of questioning and confronting the use of concepts. Additionally, referring to the diversity of the concept of quality of life and to the heterogenic population of patients living with AF, the paper contributes to suggesting both qualitative and quantitative data sources in order to elaborate on the patient perspective.

6.2. PAPER 2

6.2.1. METHOD

The paper is an epidemiological observational cross-sectional study based on data from self-reported health questionnaires (SF-36v2) completed by participants in the Danish Diet, Cancer and Health study, at the time of follow-up (1999-2002) (Tjønneland & Overvad 2000; Tjønneland et al. 2007). Based on the selection process described and displayed in a flowchart in Figure 1 in the paper, the study population consist of 42,598 participants out of 160,725 invited in 1993-1997, of whom 57,053 accepted to participate at baseline, 54,213 were eligible for invitation to follow-up and 44,874 participated in follow-up. Exposure variable is based on identification of participants with the diagnosis of AF and/or atrial flutter in the Danish National

Patient Registry (Lyng et al. 2011) at the time of follow-up. Outcome variable is based on results from the SF-36v2 questionnaires (Maruish 2011). SF-36v2 is a standardised health status assessment tool consisting of 36 questions regarding self-reported health. The questionnaire reflects self-reported health for the last four weeks. From these questions, eight subscale scores (physical function, role physical, bodily pain, general health, vitality, social function, role emotional, mental health) and two component scores (physical component score and mental component score) can be calculated (Maruish 2011; Bjoerner et al. 1997). Physical Component Score and Mental Component Score constitute the outcome variable of the study. All subscales are included in the calculation of component scores, in an algorithm based on US norms and with either positive or negative weight. All scales report a score between 0-100, with a higher score indicating a better self-reported health status. SF-36v2 is widely applied in the context of nursing care (Maruish 2011). Potential confounding factors and effect modifiers are identified *a priori* based on a literature review. Depression is considered an intermediate variable for the association, and is therefore not included as a variable in the model. The validity of the diagnosis related to depression in the National Patient Registry is considered low, because the diagnosis is often given in general practice. Additionally, would information from the Danish Prescription Database (Johannesdottir et al. 2012), only provide information on persons in medical treatment for depression, which is a likely underestimation. Gender and age are considered potential effect modifiers. Accordingly, we considered possible confounding from comorbidity. The Charlson Comorbidity Index (Charlson et al. 1987) is used as a proxy for potential confounding from comorbidity. All analyses are stratified on gender. Unpaired t-test is used to compare crude mean scores in the two groups ('AF' and 'non-AF'), and adjusted analysis is performed using multivariate linear regression models (Kirkwood & Sterne 2008). Age is entered into the model as a restricted cubic spline (Harrell 2001). Grouped as three levels of comorbidity (no comorbidity, mild level of comorbidity, and severe level of comorbidity), the Charlson Comorbidity Index scores are entered into the model.

6.2.2. MAIN RESULTS

Of 42,598 participants included in the study (19,917 men; 22,681 women), 873 (598 men; 275 women) have the diagnosis of AF and/or atrial flutter. After adjusting, a significantly lower physical component score is reported amongst both male and female atrial fibrillation patients. No systematic differences in the mental component score are observed.

6.2.3. CONCLUSION

Statistically and clinically significantly lower physical components of health status among patients diagnosed with atrial fibrillation and/or flutter, compared with the remaining participants in the cohort, are reported. However, no systematic difference in mental component scores was found. The tendencies are evident for both men and women. Applying these results gained from standardised questionnaires in a clinical setting, the context of a patient's unique situation with AF as a whole needs to be taken into account.

6.2.4. CONTRIBUTION

Even though Paper 2 takes the heterogenic patient population into account by providing the sample size, allowing for the needed stratification of analyses related to age and gender, and adjustment related to potential confounding from comorbidity, it reveal limitations and issues for discussion related to selection problems, information problems and confounding.

6.2.4.1 Selection problems

The importance of examining a large study population, providing a high statistical power, has been emphasised in earlier studies (Aliot et al. 2014; Thrall et al. 2006). The study population in this study is large and likely to represent a sample of a general Danish population in the age span between 53 and 72 years of age. Despite a large sample size, a likely underestimation of the impact on mental component score is suspected. This under-estimation is potentially due to under-representation of

participants with lower socio-economic status in the study population (Tjønneland et al. 2007). Accordingly, another study is needed in order to clarify this relationship.

6.2.4.2 Information problems

In line with existing knowledge, Paper 2 contributes with likely impact on physical components of self-reported health from AF in a Danish context. Implication of this impact is, however, complex. The impact is most likely due to other factors than the diagnosis in itself. For example:

- symptom burden with variation and hemodynamic deterioration leading to unpredictable physical ability
- treatment strategy with potential side effects of drugs, and complications related to invasive interventions
- burden related to hospitalisation and frequent check-ups in general practice.

Apart from the chronic type, AF is paroxysmal or persistent, meaning AF can come and go, from time to time. Additionally, a patient can live without noticing an asymptomatic AF, and the burden of symptoms is thus not directly related to the arrhythmia. From the validation study on the diagnosis of AF in the Danish National Patient Registry, based on participants from the Diet, Cancer and Health cohort, it is documented that nearly half of the patients (47% of the men, and 55% of the women) have sinus rhythm at discharge (Rix et al. 2012). This implies that some of the participants grouped as diagnosed with AF in our study is likely to have sinus rhythm at the time of reporting their self-reported health. An electrocardiogram for documenting AF, at the time of completion of the questionnaire could have illuminated this issue further. Moreover, as discussed in the paper, using a generic tool at only one point in time is a limitation. The study thereby contributes to emphasising the recommendation of developing and applying disease-specific questionnaires with focus on burden from symptoms (Aliot et al. 2014).

6.2.4.3 Confounding

With women in general reporting a lower score compared with men, the study reveals documentation of differences between men and women in the association. This difference is well known (Maruish 2011) and has earlier been linked to higher age, higher risk of stroke and higher prevalence of comorbidity e.g. heart failure in women with AF (Dagres et al. 2007). Stroke as a major risk factor of AF may thus imply a negative impact on self-reported health. However, another study is needed in order to clarify this gender difference more specifically.

Investigating the potential effect measure modification and the potential confounding effect of burden from comorbidity is a strength in our study, compared with earlier studies (Thrall et al. 2006; Hagens et al. 2004; Aliot et al. 2014). The results of Paper 2 thereby implies future awareness of complexity, potential effect measure modification and confounding on the association between AF and self-reported health, as an element of the patient perspective.

Despite these limitations related to selection problems, information problems and confounding, and in line with earlier studies, our results report a significant impact on physical components of self-reported health. The specific content of this impact cannot be elaborated from our study. Insight into the individual variation related to a specific participant's situation as a whole will require another approach. In terms of nursing care, this paper thus implies emphasis on the need for awareness of individual variation on physical components of self-reported health. By referring to the heterogeneous population of patients, this is discussed in the paper with the need for tailored nursing (Radwin & Alster 2002; Radwin 1995), for patients living with AF.

6.3. PAPER 3

6.3.1. METHOD

Following Peter's one-year patient journey, this paper illuminates an extreme, critical and longitudinal single case (Flyvbjerg 2001; Yin 2014).

The data sources consist of:

- field notes from multi-site field observations (Wadel 1991; Marcus 1995; Wind 2008)
- the content of a reflective research diary
- transcripts from conversations between Peter and healthcare professionals on his journey
- transcripts from open, narrative-inspired interviews (Kvale & Brinkmann 2009a, pp.173–176; Kvale & Brinkmann 2009b) related to home visits including Peter and his significant others
- Peter’s medical records
- letters and information Peter received from hospital
- results from two disease-specific questionnaires – AFEQT (Spertus et al. 2011) and AF-QOL (Badia et al. 2007) – at baseline, three months, six months, nine months and twelve months
- results from one generic SF-36v2 (Maruish 2011) health status questionnaire, at baseline, three months, six months, nine months and twelve months.

6.3.1.1 Data collection

Field notes from multi-site field observations were taken during Peter’s one-year journey (Wadel 1991; Marcus 1995). The field note observations were inspired by descriptions of doing field observations in hospital settings, as negotiated interactive observation (Wind 2008). An intensive one-year relation based on continuity and confidence was central for the process of data collection. Apart from the one visit in general practice, I participated in all Peter’s other visits to the hospital and in general practice. After each visit, I wrote field notes and a reflective diary on, for example: What happened? What was said? What was the response? What happened next? Additionally, reflections on my concerns, reactions and actions related to my role and position as a researcher. When possible during the one-year journey and based on informed consent, I recorded conversations between Peter and healthcare professionals in the hospital and in general practice. Via open, narrative-inspired

interviews (Kvale & Brinkmann 2009a, pp.173–176; Kvale & Brinkmann 2009b) with Peter and his significant others, I gained access to descriptions of lived experience related to daily life, work life and family life in the journey. In preparation for every interview, I considered the purpose of the interview and memorised the aims of the study, to elaborate on lived experience, quality of life and self-reported health. As a backup and inspiration for starting and facilitating the interview, and to be aware of my pre-understanding, I wrote down a few open questions and brought them with me. For example, related to the first home visit: How did it all start? Tell me about your family? Tell me about your work? What do you like to do in your leisure time? For example, related to conversation with Peter's son and wife: Tell me about how it all started? How do you experience that Peter has AF? What do you think about the future? Most times the questions stayed in my pocket, because the interview started and progressed naturally. The process of formulating the questions facilitated my reflections and was essential in order to be aware of and strive to bracket my pre-understanding.

In order to access how Peter's work life was affected by AF I once, after further negotiations with Peter and a time period of approximately six months, visited his work place during an evening shift and subsequently gained access to participate in a 5 x 5 km relay run, where he participated with a team of colleagues.

Information from Peter's medical record (in the hospital and in general practice) and written information and letters he received from the hospital are likewise included as data sources. This is possible via permission from Peter and with the help from secretaries.

The context related to the patient perspective of living in the journey includes lived experience, quality of life and self-reported health. Information from standardised self-reported health questionnaires from five points in time, during the one-year journey is therefore also included in the study to express Peter's perspective. SF-36v2 is a generic validated health status assessment tool, for assessing generic self-reported health status (Maruish 2011). The SF-36v2 is widely applied in the context of patients

living with AF and was therefore selected in order to draw parallels to existing knowledge on the case of interest and to the results from Paper 2. In order to illuminate the validity and sensitivity of standardised health-related questionnaires to capture the burden of AF, we used two disease-specific questionnaires AFEQT (Spertus et al. 2011) and AF-QOL (Badia et al. 2007) in combination with SF-36v2. These two were selected due to the following criteria:

- both patients and healthcare professionals were involved in the process of developing the questionnaire
- the questionnaires were validated
- the questionnaires were designed for clinical trials
- the questionnaires were not too time-consuming to fill in.

AFEQT and AF-QOL were selected in favour of Canadian Cardiovascular Society Severity in AF (CCS-SAF), Quality of Life in AF patients (QLAF) and the Short Symptom Scale for patients with AF (SSS-AF). All five questionnaires were located based on a literature review, on ‘quality of life’ and ‘atrial fibrillation’ in CINAHL, PubMed and the Cochrane Library performed in January 2011.

AFEQT is an American-developed AF-specific health-related quality of life questionnaire reflecting perception of self-reported health-related to AF during the last 4 weeks. AFEQT comprises 20 questions and reports five scores; overall AFEQT score, symptoms, daily activity, treatment concern, and treatment satisfaction (Spertus et al. 2011). All scores range from 0-100 with 0 corresponding to complete disability and 100 corresponding to no disability.

AF-QOL is a Spanish-developed AF-specific questionnaire, reflecting the last 30 days. AF-QOL comprises 18 questions that can be transformed into three scales; psychological dimension, physical dimension and sexual activity. All scores related to perception of psychological, physical, and sexual dimensions of well-being, as a part of the concept of quality of life, when living with AF. From the subscales, a global score can be calculated (Badia et al. 2007; Arribas et al. 2010). All scales report a

score between 0-100, with a score of 0 showing the worst possible health state and a score close to 100 showing the best possible health state of the patient with AF.

Permissions for using the three questionnaires in the study were obtained by contacting the developers. AF-QOL has been translated and has earlier been applied in a Danish context. AFEQT was translated to Danish by another PhD student in my department and in collaboration with the developers. The translated version of AFEQT has been validated with 20 in-patients admitted due to AF. This translation and validation process included forward and backward translation, and the process revealed no remarks. However, these validations of translations have not yet been published.

6.3.1.2 Data analysis

For the qualitative data analysis, a phenomenologically inspired approach of meaning condensation was used in a hermeneutical-phenomenological analysis process (Giorgi 1997; Kvale & Brinkmann 2009a; Kvale & Brinkmann 2009b). The phenomenological attitude, phenomenological reduction, was in particular applied in the process of collecting data, striving to bracket my pre-understanding, and to be open and aware of what Peter and other participants told and showed in the situations. Also, in the process of meaning condensation, we as co-authors kept reminding each other of this attitude, being open towards how life phenomena were expressed in the real world context of Peter's journey. All along the process of analysis, seeking the most invariant meanings of the context, all co-authors participated actively as a team. By open coding meaning units were located from the field notes, transcripts and notes from my reflective diary. NVIVO 10 software was used to structure the large amount of qualitative data from field notes and transcripts. The qualitative data analysis process, inspired by descriptions by Giorgi (1997) and the approach by Kvale and Brinkmann (2009a), consists of five steps (also displayed in Table 2 in the paper):

- Step one: Global reading – Overall impression of all data – What is being said?

- Step two: Identification of meanings and themes – Locating meaning units in everyday language – What is it about?
- Step three: Transformation of meaning units to condensed meanings and themes – Transforming meaning units into condensed meanings and themes, verifying by taking them back to data – What do we understand, what it is about?
- Step four: Organisation of the themes found – Organising themes and relating them to the aim of the study, creating central themes – Central themes relevant for the study.
- Step five: Descriptions of central themes – Describing central themes in meaning giving text – Meaningful text expressing the content of the central themes.

The stepwise analysis process was facilitated by using schedules. An example of a schedule for developing themes is displayed in Table 3 in the paper; likewise an example of a schedule applied for developing central themes is displayed in Table 4, also in the paper.

Raw scores from questionnaires were calculated into scales by using EpiData 3.1 software for AFEQT and AF-QOL and QualityMetric Health Outcomes Scoring Software 4.5 for SF-36v2. The scores from the questionnaires were inspected for exceptional patterns of changes during the journey. In order to elaborate on Peter's lived experience and self-reported health in his journey, narrative weaving as a technique, and not a design, for integrating qualitative findings and quantitative results (Fetters et al. 2013) was used to integrate central themes from qualitative data analysis and exceptional patterns in results from questionnaires.

6.3.2. MAIN RESULTS

Peter's one-year journey consists of 38 visits to general practice, two ablations in the hospital and five outpatient visits. Peter finds it hard to manage responsibility and detect reactions from his body along his journey. Despite two ablations, physical

limitations affect Peter's daily life. His family life is impacted by his failure to involve his significant others. He preserves hope for a cure throughout his journey. Even though Peter discovers that his sport watch with a basic-heart-rate-monitor can help him detect his AF, it is hard for him to decide whether his unpredictable, limited and changing physical ability is due to AF, weight gain, being out of shape, or flu. Peter experiences a lack of balanced communication, which increases his struggles remembering, and understanding information given by healthcare professionals and navigating the healthcare system. When searching for confirmation, Peter often experiences being pushed back with the responsibility, resulting in him putting his dignity in jeopardy. Receiving large amounts of written information prior to examinations is insufficient for Peter. He just recognises time and date of the new appointment and neglects to read the rest of it. Along the one-year journey, Peter tends to adjust to the situation with physical limitations, and to adjust goal setting for running. He experiences that the event of becoming a grandfather actually facilitated his process of adjusting to the situation. Physical limitation is most clearly seen in the scale of 'daily activities' in AFEQT. Starting to adjust to the situation by changing goal setting for running is in line with an increased mental component score in SF-36v2. Experience of being older and living with a disease is evident in the scale of 'role emotional' in SF-36v2. By prioritising to keep up with his job and consequently having to rest on the couch after end of work, his work life is only limitedly affected by AF.

6.3.3. CONCLUSION

It is hard to manage responsibility in the journey and detect reactions from the body indicating when to react. With rejection and self-blame for not being able to remember certain details related to the journey dignity is at stake. Lack of reflective support from professionals, lack of balanced and tailored information and lack of communication between the hospital and general practice increase the challenges of navigating the healthcare system. The AFEQT reports physical limitation better than AF-QOL and SF-36v2. A discrepancy between the scale of 'symptoms' and 'daily activities' contributed to a discussion on Peter's struggles recognising bodily reactions, and

symptoms. An increase in the mental components of health status is seen related to adjusting to living with AF, becoming a grandfather, and changing goal setting for running.

6.3.4. CONTRIBUTION

Paper 3 contributes information especially related to responsibility and the importance of dignity. The paper thereby contributes to the existing knowledge on the difficulties of accomplishing balanced information (Altiok et al. 2015; McCabe et al. 2015), concerns of being marginalised, and a struggle to be believed (McCabe et al. 2015; Altiok et al. 2015; Withers et al. 2015). The emphasis of the paper is on the need for patients to be met with respect for their dignity. Furthermore, the paper contributes by elaborating on the challenges related to being a patient and having to navigate in a healthcare system consisting of sectors, and with its own traditions, rules and pathways. Existing knowledge provided by McCabe et al. (2015; 2011), Altiok et al. (2015), Ekblad et al. (2012) and Withers et al. (2015) reports patients being uninformed, unsupported and lack of counselling and having difficulties interpreting their symptoms. The in-depth descriptions in Paper 3 are thus an important contribution to the existing knowledge, also for healthcare based across sector boundaries. The paper contributes by elaborating on how it takes time to adjust to a situation of living with a chronic condition – a perspective, which is essential to keep in mind in the daily contact with patients.

The longitudinal design and a period of a year were important for facilitating access to situations in Peter's journey, and to gain insight into the journey being placed across organisational sector boundaries, which has not earlier been illuminated. Related to family life, existing knowledge already reports significant others to be affected by AF in their daily life, and quality of life (Dalteg et al. 2014). However, results from Paper 3 contribute with descriptions of dynamics between Peter and his significant others, outlining how their relation changed by Peter becoming more willing to share concerns with his son and wife at the end of the study. In terms of impact on work life, descriptions of Peters tendency to hide his tiredness and keep up with his work,

and then having to rest on the couch after work, support existing knowledge on experience of a stressful situation of keeping up with a job, when living with AF (Withers et al. 2015). The suggested financial burden of frequent check-ups in existing knowledge (Altiok et al. 2015) was however not evident for Peter. Peter tended to arrange frequent visits in general practice in his leisure time and was only off from work during the two radio frequency ablations. Furthermore, he went by bike when he needed to visit the hospital or his general practitioner. Previously suggested financial burden related to transport (Altiok et al. 2015), was not of concern for Peter. Access to visit Peter at his workplace and to meet with his family requested confidence. A year was therefore found to be appropriate, because access to observe Peter in his interaction with his colleagues was not gained until at the six-month stage of the data collection. This access was particularly important, because despite having AF, it was of high priority for Peter to keep up with his work, and by being employed full-time, he spends most of his time at work.

From existing knowledge, limited access to unique variation by capturing the patient's perspective from using a standardised generic or disease-specific questionnaire has been debated (Carr & Higginson 2001; Moons 2004; Aliot et al. 2014; Mark 2016). This struggle is exemplified in Paper 3 by assessing the impact from AF in AFEQT in the scale of 'daily activities', and not in the scale of 'symptoms'. The patient's struggle recognising bodily reactions and symptoms is important to keep in mind, when the patient perspective is accessed from a standardised questionnaire. The results from questionnaires were calculated after ending data collection, because I wanted the phenomenologically inspired attitude, focusing on Peter's lived experience and narratives to guide the conversations. Interestingly, AF-QOL reveals an exceptional decrease in aspects related to the subscale of 'sexual activity' throughout Peter's journey. This dimension is not displayed from AFEQT and SF-36v2. Furthermore, sexual activity is not elaborated further in my conversations with Peter, and in Peter's conversations with the healthcare professionals. The three questions in the AF-QOL related to the score for the subscale of 'sexual activity' are related to; medication, less frequent sexual activity after been given the diagnosis, and being

afraid of getting the arrhythmia during sexual activity. To gain an impression of whether this is an important issue, it could be interesting to ask Peter about his concerns in relation to his sexual activity, this was however not possible because I calculated scores from questionnaires after ending data collection. As illustrated by this example, application of questionnaires can be a limitation, because they only capture predefined information. Context and complexity are accessible from a qualitative approach. Accordingly, Paper 3 contributes information on the synergetic of combining descriptions context and complexity of lived experience, from daily life, family life and work life with knowledge on magnitude of the patient perspective on self-reported health, gained from a questionnaire.

CHAPTER 7. METHODOLOGICAL CONSIDERATIONS

This section will focus on methodological considerations related to:

- strengths and limitation of the case study design
- inter-subjective objectivity, as a reliability criterion of the interpersonal knowledge gained in the process of data collection for the case study
- strengths and limitations of applying standardised questionnaires.

7.1. STRENGTHS AND LIMITATIONS OF A CASE STUDY DESIGN

An important strength for a case study design is the ability of embracing, different type of research questions, different research traditions, and different type of knowledge (Yin 2014; Flyvbjerg 2001). Selection of relevant data sources is based on the case of interest. The combination of quantitative and qualitative data sources is a strength when investigating the patient perspective.

This dissertation applies multiple sources of evidence. Depending on how a study is conducted, case studies can be entirely consistent with a mixed-methods study (Flyvbjerg et al. 2012, p.20), but can also be considered as a study applying multiple sources of evidence as a multiple methods study (Creswell 2015; Yin 2014). Mixed methods are becoming more frequently used within the research context of nursing care, due to endeavouring to fathoms the complexity of research questions of interest (Creswell 2015; Creswell 2008). Accordingly, the case study design is mentioned as an advanced mixed method framework (Fetters et al. 2013). Crucial for a mixed method approach is the 'mixed' research question, calling for a design with a mix of methods and integration of both qualitative and quantitative data. Integration on both design, data, methods and reporting level is central (Fetters et al. 2013; Creswell 2015). The three research questions in this case study are investigated separately, as three embedded units of analysis. This dissertation has not a new mixed methods

research question, based on the three research questions derived from the aim, as requested in a mixed methods design.

Another strength of the case study approach is the detailed and in-depth investigation of a phenomenon; this is particularly beneficial for investigating the complexity and magnitude of the context of the patient perspective. Moreover, providing in-depth descriptions of the case of interest is likely to attract a broader readership, from different traditions. This is also important for elaborating the overall patient perspective of the journey with AF.

One common limitation related to a case study design is selection of case (Yin 2014). In order to prevent exclusion of cases illuminating contradict theory, detailed description of existing knowledge, design, case of interest, study outline and especially Paper 1 supporting the theoretical base for the study has been important for the case study design

A pitfall related to an embedded case study design is if focus is placed only on one unit of analysis, and not on the overall level of the study (Yin 2014). We have tried to eliminate this issue by focusing on the overall patient perspective – the whole story about the patient perspective. Specific examples from Peter's journey are thereby taken to a higher level – relating the examples to existing knowledge, results from the other papers and theory.

Generalisation related to case studies is another common limitation. In a case study generalisation can be considered as recognition of patterns and an analytical generalisation, not a statistical generalisation (Yin 2014, p.40). An analytical generalisation implies the opportunity to shed light on context of concepts and principles. The theoretical base for the case study forms the analytical generalisation, thereby on how results from the case study contribute to existing knowledge (Yin 2014). Related to the holistic worldview, a situation involving human beings can be considered to contain both universal, typical and unique patterns. After recognition of universal and typical patterns, these need to be presented for practice, and practice

need to recognise them (Delmar 2010). In-depth descriptions of lived experience provided by a qualitative inquiry can facilitate the opportunity of recognising human life patterns from one unique case in a new situation. However, this process requires a reflected attitude towards the unique context of the case of interest. By means of a conscious reflective process, Peter's lived experience is likely to facilitate decision-making in a new unique patient's situation. Knowledge based on one study always has to be understood in the context of where it originates. Actively, in dialogue with practice, it can be related to the context of a new situation. Recognition is thereby an active and demanding process based on a close dialogue with practice (Delmar 2010).

The case of interest is investigated in its real-world context. Access to the case 'site' for in-depth data collection has also earlier been suggested as a limitation for a case study (Yin 2014). This was in particular experienced related to the process of data collection for Paper 3. This process implied my engagement where I gained access to the field through Peter. My access was gained gradually as our relation build-up. Access to the field with me being the only researcher collecting data, could have led to hiding important information. We consider the opportunity of getting close to Peter, his significant others and colleagues, would have been limited if we had alternately chosen to be more researchers or different researchers present in the process of data collection. Even though I was the only one engaged in Peter's journey, the other co-authors supported my reflection in the process of data collection, by being a reflective and functional team. Accordingly, we all participated actively in the process of analysis. For Paper 1 and Paper 2, the access was not critical, because Paper 1 is based on a systematic literature search and Paper 2 on data from questionnaires collected beforehand.

7.2. INTER-SUBJECTIVE OBJECTIVITY

Data collection in the case study incorporates among other data sources participant observations, and qualitative interviews. These results express relational knowledge as I am an active part of data generation through participating in Peter's journey.

Illustrated from examples of my role as a researcher related to being labelled ‘bodyguard’ (example no.1), engaging in Peter’s journey in order to achieve completeness of data (example no. 4), and my considerations related to ending data collection (example no. 6), it is a committed process to collect data of this kind. Accordingly, facing and managing unexpected reactions from the field (example no. 5) was also essential for accessing this data.

Understanding is not only related to one’s own pre-understanding (Gadamer 2007) but also to inter-subjectivity as grasping or comprehending the meaning of something from the person’s own perspective (Jupp 2006). Inter-subjective understanding is different from subjective understanding and considered objective when the understanding is accessible to two or more minds, thereby depending on a reasoning and comprehensive argumentation for examples of descriptions of context (Ragans 2012, p.149). Objectivity has been discussed within social sciences and is suggested to be considered ‘situational objectivity’ (Williams 2015). Inter-subject objective knowledge requests an active, conscious, and reflective adaptive process and calls for description of the role as a researcher. Descriptions of the six examples related to my role as a researcher is thereby reliability criteria for the result of the study. Understanding and acknowledgement of my role as a researcher are therefore crucial for understanding the results from Paper 3.

With Peter as the main participant, dropout would be fatal, as it would result in the end of data collection. My role as a researcher was therefore also important for eliminating the risk of dropout. This challenge was further elaborated by exemplifying my need for engaging in Peter’s journey, in order to achieve completeness of data. It is well known that the quality of data collection from participant observations and interviewing depend on the quality of the relation between the participants and the researcher (Wadel 1991; Spradley 1980). The only access to lived experience goes through human engagement, being present in time and space with the participant (Gammeltoft 2010; Tjørnhøj-Thomsen 2010; Fog 2004). My engagement was therefore essential for collecting data. Establishment, facilitation, preservation, and ending the relation with Peter in a respectful manner requested for closeness.

Establishing and preserving an analytical distance were likewise essential for the study methodology. Examples from reflections related to my role as a researcher are displayed to illustrate the fine balance between being close and preserving an analytical distance in my relation to Peter. This balance can be referred to the researchers need for being simultaneously faithful to the specific case of interest, and ‘faithless’ and open to what happens in a specific situation (Martinsen 1993). As suggested by Gammeltoft (2010, pp.284–285), I must put myself (as a researcher) in Peter’s position, daring to challenge my own pre-understanding and knowledge taken for granted – acknowledging him as a human being and not only as a patient. This process was facilitated by the phenomenological inspired approach (Giorgi 1997; Kvale & Brinkmann 2009b) of the attitude of phenomenological reduction, striving to bracketing my own pre-understanding, being open and present in the moment with Peter in his journey. The relation between a researcher and a participant is characterised by a scientific and time limited purpose and not a ‘real’ mutual friendship (Fog 2004). My position as a researcher thereby implies an ethical demand. I faced this demand by constantly reminding myself about seeing Peter as unique, with his own history and experience of a given situation, and not only as a mean toward collecting data for the scientific purpose. Ending the relation with Peter as exemplified from example no. 6, was therefore also my concern from the beginning of data collection.

7.3. STRENGTHS AND LIMITATIONS OF APPLYING STANDARDISED QUESTIONNAIRES

A strength of using a standardised questionnaire is access to knowledge on a population of participants – for example to express the magnitude of the patient perspective. This is important related to statistical generalisation (Yin 2014). Different tools are likely to capture different aspects of quality of life e.g. self-reported health. A standardised questionnaire is thus limited to contribute with what it is design for. As debated from Paper 1, it is therefore important to consider how quality of life is defined, what aspects are of interest, and subsequently what approach will be the most appropriate for accessing knowledge on the aspect of interest. Is the selected tool

sensitive for capturing knowledge on the research question of interest? A previously published scientific research paper has questioned if quality of life measures are patient-centred, due to being standardised, and thereby not necessary giving the opportunity to report subjective variation (Carr & Higginson 2001). In order to maintain the subjective impact and variation, including an ability to weight the importance of aspects from the questionnaire is therefore recommended.

The participants in the Diet, Cancer and Health study are presented with a generic tool (SF-36v2) (Maruish 2011). Despite being an expression of the participant's self-reported health, SF-36v2 assesses a pre-defined perspective on health status, based on 36 questions. Apart from two questions related to overall impression of health and overall health compared to a year ago, this questionnaire is limited to capture predefined aspects of self-reported health. As discussed in Paper 2, a disease-specific questionnaire would have been preferable. Data collection for the study was done beforehand (1999-2002), and no disease-specific questionnaire was available at that time, therefore we had no influence on the selection of questionnaire.

Related to data collection for Paper 3, Peter expressed that due to variability in his physical condition, it was hard for him to tick the 'right' boxes. He reported that it took him lot of time to read, understand and fill them in. In the conversations with Peter, I kept encouraging him to do his best to fill them in, pointing out that there are no 'right' or 'wrong' answers. The three questionnaires applied in Paper 3 have slightly different time scales. AFEQT and SF-36v2 report within the last four weeks, whereas AF-QOL reports on the last 30 days. Being presented with all three questionnaires could potentially increase the difficulties in filling in the three questionnaires.

Staff members of the Diet, Cancer and Health study managed data collection for data applied in Paper 2. The questionnaires were distributed to the participants as part of a larger questionnaire on lifestyle and dietary intake, by ordinary mail, and with a request for filling in and returning likewise by mail. From the staff members who collected data, it is known that a large effort was made to contact participants when

distributed questionnaires were not returned. However, no information reveals about the participant's potential struggles of completing the questionnaires.

As reported from Paper 3, the scale of 'daily activity' in AFEQT (Spertus et al. 2011) is the most appropriate to capture Peter's expression of physical limitation. The scale of 'symptoms' is less likely to capture Peter's experience of this limitation. The questions regarding symptoms reflect understanding and sensation of common symptoms associated with AF such as palpitations, irregularly heart rhythm, pauses in heart rhythm, and feeling unwell and dizzy. By questioning: limitations in performing physical exercise due to breathlessness, limitations in doing things together with family and friends, carrying groceries and climbing stairs, and difficulties lifting heavy stuff and doing demanding activities, the scale labelled 'daily activities' is directly related to limitations in daily life.

This difference in scales is likely to be related to difference in patients' and healthcare professionals' perspectives on bodily reactions and what is considered symptoms. The challenge for patients detecting bodily reactions and translating these to what a healthcare professional consider symptoms, has earlier been discussed by Eriksen and Risør (2013). Furthermore, there is a potential risk of problems if the participants receive too much information or experience a lack of support in the procedure of filling in questionnaires and understanding the questions previously raised (Aliot et al. 2014). As discussed in Paper 3, patients need obvious symptoms to justify that they have a chronic condition. Peter just feels tired and in a bad shape. For Peter it is a struggle to detect which of his bodily reactions are due to AF. Is his tiredness and limited physical capacity due to AF, less physical activity, his 10-kg weight gain, or flu? The limitation of capturing unique details from a standardised questionnaire is further exemplified from the unexpected result of no systematic difference in the mental component score in Paper 2. A patient reports what he or she understands for the questions provided. This is not necessarily the same understanding held by the researcher investigating the questionnaire. This issues related to understanding of the questions in a questionnaire is therefore important to bear in mind, and shed light on the need for validating a questionnaire. This perspective on limitations related to the

use of questionnaires adds to the importance of considering specific questions posed in a questionnaire and the validity related to the patient perspective.

In this dissertation, we used SF-36v2 both on the population level in Paper 2 and on the individual level in Paper 3. Accordingly, there is difference in applying questionnaires on a population level and on the individual level. From the manual for SF-36v2, differences in minimal clinical difference are suggested (Maruish 2011). Moreover, it is emphasised that the best comparison is evaluating self-reported health over time on the individual level. Comparing self-reported health, between two populations therefore need to be interpreted with caution, because the difference can be due to difference in participants' evaluation of their health.

CHAPTER 8. DISCUSSION

This chapter elaborates on the complexity and magnitude of the context of the patient perspective of the journey with AF, including quality of life, lived experiences and self-reported health status. In particular, Paper 3, contributes with examples on the importance of promoting and preserving the patient's dignity. Based on these examples, upholding dignity to support the patients' autonomy is discussed with the shifting perspective model of living with a chronic condition. The goal for autonomy and responsibility in this relation are discussed with typical male and proactive behaviour. The discussion section will thereby elaborate on the patient's process of getting through the healthcare system in their journey as a 'whole' person, and not only as a patient with a disease. A person-centred holistic view on the journey across organisational sector boundaries is central. This view is discussed in the last section of the chapter with the process of being in transition, which is a central concept for nursing care. The discussion section is therefore structured from the following points; dignity in shifting perspectives, autonomy and responsibility, and a person-centred holistic view in a process of transition. The discussion is based on examples from Peter's journey in Paper 3, discussed with existing knowledge and theory, related to the results from Paper 1 and Paper 2.

8.1. DIGNITY IN SHIFTING PERSPECTIVES

Peter's struggles with: physical limitation, balancing responsibility, navigating the healthcare system, and obtaining balanced information are discussed with the interdependency, trust and mutual respect between humans was described in Paper 3. These struggles are likely to put his dignity at stake. Preserving and promoting the patient's dignity is fundamental for the human existence (WHO 2016) and for healthcare (Jacobs 2001; Chochinov 2002; Chochinov 2007; Chochinov 2013a; Nordenfelt & Edgar 2005). Dignity is multifaceted, complex, and implies respect for

the human lived life with choices to be made (Delmar 2013; Jacobs 2001; Chochinov 2007).

Dignity has been of interest for a variety of conditions. For example: end of life care (Chochinov et al. 2015; Van Brussel 2014), long term care (Kane & de Vries 2016), patients living with serious illness (van Gennip et al. 2013), patients living with multiple sclerosis (Sharifi et al. 2016), patients' undergoing surgery (Rasmussen & Delmar 2014), and for residents' in nursing homes (Høy et al. 2016). Based on a narrative review on dignity, Lin and Watson (2012) stated that opening the discussion of the content of dignity is essential for a clinical healthcare setting, in order to prevent dignity only being a rhetoric matter. Every human being knows what can preserve and hinder his or her dignity. Related to the field of surgery in Denmark, the patient perspective has therefore been emphasised as the key to understanding the empirical content of dignity (Rasmussen & Delmar 2014). According to the context of patients living with multiple sclerosis (Sharifi et al. 2016), patients receiving long-term care (Kane & de Vries 2016), and end of life care (Chochinov et al. 2015; Van Brussel 2014) the interaction between personal and social factors are debated to influence the person's experienced and inner dignity. Focusing on the patient's life as a whole can therefore help to identify dignity-promoting and dignity-threatening factors. Related to residents in nursing homes, dignity has been described as an ongoing process (Høy et al. 2016). This process is based on opportunities of being involved as a human being, as the person one is and strives to become, and confirmed in interaction with significant others and the society. Reported from the field of surgery, trust and mutual respect, and being an important person worth spending time with are furthermore essential for dignity (Rasmussen & Delmar 2014). In relation to suffering from a serious illness, Gennip and colleagues (2013) developed a model including factors related to the individual-, the relational- and the societal- self, based on the statement that patient's dignity is not necessarily affected directly by the disease, but more indirectly affecting the way the patient experience themselves. This is in line with what Baillie (2009) found in an acute hospital setting, that dignity is related to; feeling comfortable, in control and being valued. In order to preserve and promote dignity,

every patient therefore needs to be met with respect and an open attitude towards his or her unique situation and as a whole human being (Chochinov 2013a; Merleau-Ponty 1962).

According to the shifting perspective model (Paterson 2001), whole human beings live in a dialectic dynamic between the feeling of wellbeing and the feeling of illness. Based on a meta-synthesis on 292 qualitative studies on the patients' lived experiences, the model was developed in order to explore shifting perspectives of living with a chronic condition (Paterson 2001; Paterson 2003). Wellbeing – being in control and feeling comfortable, implies thinking rational. Illness – being in a vulnerable situation with an increased need for support. Because human feelings are likely to have a tendency of being out of rational control, illness implies thinking less rational. The perspective of illness is linked to living with a chronic condition like AF, and implies being in a vulnerable situation. Related to the human dignity, life with a chronic condition implies balancing the dialectic relationship between wellbeing and illness, in order to achieve the feeling of being in control, feeling comfortable and being valued as a whole human being (Baillie 2009).

The shifting perspective model (Paterson 2001; Paterson 2003) demonstrates how symptoms related to a chronic illness can be in the foreground in some situations, and from time to time can push wellbeing in the background. The perspective can eventually change so that wellbeing becomes the foreground and illness the background. A paradox exists in both wellbeing and illness being important for life with a chronic condition. Living with a chronic condition is not only a question of acceptance. When illness is in the foreground loss, sickness, suffering and burden from living with the condition is in focus. Illness in the foreground may facilitate the patient's process of becoming familiar and comfortable with the body's reaction on the condition. Loss of control – e.g. related to Peter's experiences of progression in disease by being physical limited, combined with lack of skills to navigate are thus likely to promote a move from wellbeing to illness. On the other hand, support, optimism, and hope can facilitate a move from illness to wellbeing. Acceptance of a disease is according to the model, a question of letting the feeling of wellbeing be

important for the human life, also in life with a chronic condition. Achieving the needed support, loss and limitations can thereby facilitate a shift in perspective to wellbeing in the foreground. The model thereby demonstrates that life with a chronic condition from the patient perspective is a dynamic and unpredictable process. Depending on the patient's situation as a whole, the patient may need support for promoting both illness and wellbeing. For Peter, being physically limited in running, biking and climbing the stairs and the weekly reminder of going to the nurse in general practice for a blood sample, were likely to restrain him in the perspective of illness in the foreground, and being in the role as a patient. However, other events in his daily life, family life and work life, for example becoming a granddad and keeping up with his job, were likely to shift his perspective to wellbeing in the foreground. Keeping up with his job might preserve his feeling of being in control and feeling comfortable related to his work life. His tiredness, however, caused limitation in accomplishing what he used to do in his leisure time and in the time with his family. This effort of keeping up with his job thereby caused major impact on his daily life and family life. This is an example of living in the paradox, balancing between wellbeing and illness, respectively, in the foreground or in the background of life (Paterson 2001). For Peter, the positive effect of becoming a granddad facilitated his adjustment to the physical limitation and made him change goal settings for running, and thereby to shift perspective to wellbeing. This led to a new way of being comfortable and in control, by focusing on spending time with his grandchild.

Illustrated by example no. 2 from Chapter 5, being able to run means quality of life to Peter. The physical limitation related to AF was thereby likely to shift his perspective of illness in the foreground. Thus, after living with the condition in more than 10 years, Peter's general practitioner has already adjusted his situation of living with the condition, and shifted his perspective to wellbeing, by being satisfied with walking instead of running. Being met with the message from his general practitioner 'why don't you just stop running' Peter is disappointed. This disappointment is a likely sign of not being met with an open attitude towards his perspective on the situation and difference in perspectives of the importance of running for Peter and his general

practitioner. Demonstrated by Peter's journey a shift in perspective from illness to wellbeing takes time.

Peter went home blaming himself for going. As earlier discussed by Delmar (2013) self-blame and losing control can be a threat to dignity. Peter's tendency of blaming himself for being too stupid to understand the provided information and for recognising what is most important is a likely example of the combination of self-blame and losing control. Reported in Paper 3, Peter is very polite in his direct contact with healthcare professionals, and does not consider himself as special. At work when he is talking to his colleagues, he is in contrast not keen on being direct, a likely sign of him feeling comfortable among colleagues. In the hospital in reply to the well-intentioned question, 'So do you have any further questions' at the end of a conversation, eventually being a cliché on the way out of the door, typically Peter will just say 'No', and then explain to me afterwards that he had no clue of what to ask about. Questions usually occurred to him on the way back home after the visit to the hospital or general practice. Based on Peter's experience, not being met with an open attitude towards his actual and personal situation, combined with a tendency of keeping things close and blaming him-self, can lead to feeling less comfortable, being out of control and as a result put his dignity at stake and increase his level of self-blame.

Both the concept of quality of life and dignity are universal and dynamic, containing typical patterns for human beings. Based on Paper 2 and earlier studies (Dorian et al. 2000; Perret-Guillaume et al. 2010; van den Berg et al. 2001; Lioni et al. 2014), a significant impact on the physical component score of self-reported health, can typically be expected from patients living with AF. With health status being a dimension of quality of life, and the significant reported physical impairment, there is a need for approaching the physical component in patients living with AF. How much an impaired score affects a patient's whole situation is thus unpredictable. Being physically active and maintaining habitual activities in daily life, family life and work life are related to dignity; being in control and feeling comfortable. According to the shifting perspective model the impact will likely change between foreground and

background depending on individual variation. For Peter, physical components of quality of life is likely impaired due to adjusting to the situation, recognising bodily reactions and being physically limited, and thereby with the feeling of illness being in the foreground. Maintaining dignity thus request for wellbeing in the foreground of most times. For Peter, being physical limited and striving to keep up with a full time job might facilitate keeping focus on wellbeing. However, this priority of work life is likely to impact with the feeling of illness being in the foreground related to daily life and family life. Expectable typical impairment in physical components of health status is thus likely to be connected to patients shifting perspectives and dignity. As illustrated by these examples from Peter's journey the unique perspective is essential for dignity (Rasmussen & Delmar 2014). Solely focusing on countable measures, as debated in Paper 1, there is a risk of losing valuable insight into the unique patient's perspective.

In order to elaborate on why the perspective of dignity is important, patient autonomy and responsibility related the journey are discussed in the following section.

8.2. AUTONOMY AND RESPONSIBILITY

An overwhelming and unbalanced responsibility is, as discussed in Paper 3, likely to put the patient's dignity at stake and challenge the patient's autonomy. Autonomy is, like dignity, essential for humans. Being a master in one's own life is important in order to promote dignity and maintain autonomy (Rasmussen & Delmar 2014; Jacobs 2001; Chochinov 2007), and according to McCabe et al. (2011) to enhance quality of life. Autonomy – being a synonym for self-management, is related to the patient's vulnerability (Delmar 2013; Thiel et al. 2001; Rasmussen & Delmar 2014). Successful autonomy thereby entails respect for the patient's individual expectations, values, and opinions. Due to the interdependency between humans (Løgstrup [1956] 2008), there is always a risk of an individual person being ignored or even rejected. Balancing and adjusting responsibility related to autonomy is a fine balance requesting for human mutual respect. If self-management becomes the ultimate goal for healthcare, too

much responsibility are likely to be placed on the individual patient (Delmar 2013; Delmar et al. 2006; Thiel et al. 2001).

A typical proactive patient behaviour has previously been described related to autonomy (Delmar et al. 2011). A proactive behaviour includes willingness to take the full responsibility of a situation. Lacking knowledge, and being met with a request for being proactive, it can be a struggle to pose questions and ask for help. Such situation can potentially lead to feelings of guilt and self-blame or even rejection. In contrast, stripping the patient for responsibility and self-determination, by being met with a possessive and clingy attitude, not being provided with responsibility at all, is likely to affect the patient's self-respect and thereby weaken autonomy. A successfully autonomy is thereby related to a fine balanced and clear allocated responsibility. When Peter in Paper 3 expresses how hard it is for him to gain support in order to manage responsibility, it could be an example of healthcare professionals expecting him to be proactive. Peter could therefore be at risk of being ignored and potentially rejected, which is likely to increase his self-blame, and be a further challenge for upholding his dignity. This risk is further increased by Peter's tendency of keeping things close.

It is evident that there is an association between masculinity and health-seeking behaviour (Mahalik et al. 2007; Connell 2007; Sjørup Simonsen 2006). Peter's attitude of keeping things close might be a typical male behavioural pattern. Typical strengths for a man is keeping control, and striving towards normality. Therefore, related to health issues, men typically tend to keep things close, waiting to see if the condition will improve, whereas women typically tend to seek faster and more frequent advice from their general practitioner (Mahalik et al. 2007; Sjørup Simonsen 2006). Acknowledging the typical masculine pattern of being in control and being normal is therefore important to be aware of in order to strength the patient's autonomy and to promote a balanced responsibility in the patient's journey. Exemplified from Paper 3, Peter explains how he benefits from talking to male fellow-patients in the hospital and from receiving a good explanation on AF from the doctor in the outpatient clinic. This doctor provides him with some clear facts about the heart,

the function of the heart and the malfunction related to AF by drawing the heart on a piece of paper and using metaphors related to pipes and pumps. These metaphors made sense to Peter, since they were familiar for him from his daily work as a machine operator. This doctor accepted his responsibility by being open towards Peter's situation as a whole, being attentive and providing information based on knowledge of Peter's profession as machine operator.

The lack of oral information, combined with conflicting and an overwhelming amount of written information received from the hospital, challenges Peter's autonomy. Peter just recognises date, place and time, and thereby misses out important information, related to the blood sample prior to the CAT-scan, and the difference between an admission and an outpatient visit. Peter thereby experiences the responsibility in the journey being pushed back on him. Despite his need for sufficient knowledge, he is requested to navigate the healthcare system on his own. He only sees his general practitioner once throughout his one-year journey. The nurse in general practice provided care at 36 visits, and due to summer holidays, he once went to a substitute general practitioner. No one provides Peter with nursing care across organisational sector boundaries in the healthcare system. Within the ever changing and busy healthcare system it is reasonable to refer to an old saying, 'out of sight, out of mind' meaning; when Peter is out of the door, you (as a healthcare professional) are no longer responsible for his situation. His general practitioner could consider that he is just going to the hospital where they will take care of the treatment. From the hospital perspective, Peter is discharged, and now it is Peter's responsibility to come back if the ablation does not work, and it is his general practitioner's responsibility to contact the hospital again when the oral anticoagulant treatment is completed. This responsibility is illustrated by Peter being questioned 'What did they tell you in the hospital?', 'What needs to be done now?', when he showed up for a visit in general practice. Peter is thereby constantly pushed back with the responsibility, which he experiences as a struggle. In the hospital Peter is questioned 'What did your doctor (general practitioner) tell you to do', 'for how long have your INR been between 2.5 and 3.5?' Fortunately, Peter recognises how important it is for him always to carry his

results from the blood tests on a small orange card in his wallet. With limited links between the sectors (hospital and general practice), this card and Peter constitutes the link.

Illustrated from this and the previous section, promoting and preserving dignity is a fine balance of responsibility, essential for a successful autonomy. The following section accounts for discussion of the need for a person-centred and holistic view on the journey as a process of transition.

8.3. A PERSON-CENTRED HOLISTIC VIEW IN A PROCESS OF TRANSITION

Living with a heart condition always matters for a patient because it concerns the heart as a vital pump for the life. Reported in example no. 2 in Chapter 5, the general practitioner expressed to me that he does not consider AF serious, as compared to his experience from his work as a doctor. In contrast, and based on cognitive interviews with 25 patients diagnosed with symptomatic arrhythmias, irrespective of how significant the heart matter is from a clinician's point of view, it is always of highly importance to the patients (Withers et al. 2015). This is mainly related to a large negative impact on quality of life from unpredictability and symptoms. Patients need to be met with kindness, humanity and respect for their perspective of their situation as a whole, because a patient's lived experience is unique and dynamic (Chochinov 2007). Discussed in Paper 2 and Paper 3 and in line with a holistic worldview, providing person-centred nursing care tailored to the specific patient's journey is important across boundaries in the healthcare sector.

Person-centred care is holistic, flexible, creative, personal and unique (Edvardsson 2015). A person-centred and holistic view on nursing care, focusing on the patients will, reason, feeling, and needs and thereby engage the person as an active partner in the process of treatment and care planning. This view implies a request for knowledge on the person behind the patient. It means considering the patient as a person, not only a patient with a disease (Ekman et al. 2011). By placing the person in the context and

not only focus on the organs or the disease, person-centred healthcare and medicine is dedicated to promote physical, mental, socio-cultural and spiritual wellbeing in harmony with reducing disease (Mezzich & Salloum 2015).

A patient journey with AF incorporates facing new and changing situations and meeting diverse locations in the healthcare organisation across organisational sector boundaries. The journey is thereby interfered by the patient's individual experience of living with a chronic condition. Being in a patient journey with a chronic condition is regarded as being in transition. Transition has been proposed to be a central concept in nursing care (Chick & Meleis 1986; Schumacher & Meleis 1994; Im 2011), because a successful transition is important for the health, wellbeing and quality of life of a human being. A transition is defined as: *"a passage or movement from one state, condition, or place to another"* (Chick & Meleis 1986, p.239). A transition is thereby an ongoing process of changes, characterised by a disruption in the persons linking to his or her situation and normal behaviour. A disruption related to a transition is thereby likely to disturb the person's security, and cause disconnectedness. The process of transition persists over time, and includes a development, flow or movement in stages or phases. Being in transition is thereby in line with the dialectic balance between wellbeing and illness in shifting perspectives (Paterson 2001).

A transition needs to include a change, for example a change related to the individual person, identity, role, patterns or behaviour, ability or relationship (Chick & Meleis 1986; Schumacher & Meleis 1994). Events, which can lead the person into a transition, include for example illness, recovery, loss, hospitalisation and retirement. A transition is therefore likely to include aspects related to the patient's daily life, family life, and work life. The theory of transition thereby reveals a holistic view on the patient's situation of a change. Transitions are characterised by patterns related to illness, development, situations and organisations. With the journey of AF being situated in the healthcare organisation, the journey is considered an illness transition with organisational patterns. Illness, recovery, loss of physical capacity, hospitalisation and the impact on work life are evident related to the patient journey with AF. A transition can be characterised as single or multiple, temporal or

permanent, pleasant or unpleasant, positive or negative, planned or unplanned, with a clear or ambiguous entry and exit, and cause minor or major disruption (Chick & Meleis 1986). For the journey with AF, the transition may be multiple, complex and ambiguous to enter as a newly diagnosed patient, because the journey is placed across organisational sector boundaries. The exit of the transition is also ambiguous due to AF being a chronic condition, of which the patient needs to live with until the end of life. The transition may be further complex when there is no clearly responsibility outline for the journey, as reported from Paper 3. How a transition impact on a patient's life will always depend on the patient's earlier experiences and expectations. The experience of the transition is thereby related to the patient's specific journey, and can cause reactions from the person, mediated by both the individual person and environmental factors.

With 38 visits in general practice regulation and monitoring of the oral anticoagulant treatment are central for Peter's journey. His few visits to the hospital are however, essential due to treatment with radio frequency ablations, and visits in the outpatient clinic. Despite visits to the healthcare system, Peter's transition continues throughout his journey. Patients like Peter are thereby to manage their process of transition on their own most of the time in their journey. Illustrated through Peter's journey and from existing knowledge (Aliot et al. 2014), patients with AF have frequent contacts with the healthcare system, both in general practice, and at hospital. Providing patients with a connected care organised in parallel silos imply a special challenge. By describing the patient journey as a battlefield, this challenge has been illustrated from the context of older chronically ill Danish patients (Kjerholt et al. 2013). According to Kjerholt et al. (2013) a large gap between values and actions in the healthcare system is from the healthcare professionals' perspective experienced as being caught in a value conflict – tempered with a feeling of being powerless, and maintain status quo in the daily work despite aiming to provide a connected care. A gap between organisational values such as a person-centred approach and an episodic focus on patients and lack of time has been suggested as hindering factors for providing patients with continuity of care. Too much focus on the disease, medical treatment, and

fragments of the patient journey, can thereby led to discontinuity of care, and challenge adjusting to the individual patient's specific situation. Acknowledging the journey as a process of transition including shifting perspectives, and the importance of information on the individual patient's perspective of own situation and quality of life, as also emphasised from Paper 1, is therefore central for the person-centred and holistic view on the journey.

CHAPTER 9. CONCLUSION

The aim of this dissertation is to explore the complexity and magnitude related to the context of the patient perspective of quality of life, self-reported health and lived experience, in the patient journey of living with AF.

In conclusion

- Suggested existence of an implicit societal agreement on health status being aligned with quality of life, imply a risk of losing valuable information on the patient perspective of living with AF. The societal agreement is seen in the scientific context by ‘tricks of arguments’ functioning as a warrant in the chain of argumentation, without further requests for documentation.
- Significant impact in physical components of health status for both men and women on a population level are demonstrated for the association between being diagnosed with AF and health status. No systematic, impact is evident for the mental component score. The results are provided based on a sample size allowing needed stratification and adjustment for gender, age and comorbidity.
- Lived experience of quality of life and self-reported health are demonstrated to impact significantly on daily life, family life, and work life in the individual level of an extreme, critical and longitudinal case by:
 - facing challenge related to responsibility in the journey
 - struggling to obtain the needed balanced and individualised information and support
 - struggling to navigate the healthcare system
 - struggling to find the connection between bodily reactions and symptoms
 - being at risk of being rejected and loss of dignity
 - being requested to adjust to a new situation with unpredictable physical ability

- Acknowledging and supporting the patient's shifting perspective of illness and wellbeing can preserve and promote the patient's dignity.
- Preserving dignity, minimising self-blame and balancing responsibility is likely to strengthen the patient's autonomy.
- Management of autonomy is related to typical proactive and male behavioural patterns.
- A person-centred and holistic view on the journey as a process of transition, embracing organisational boundaries in the healthcare system is needed in order to provide the patients with a connected journey.
- Combining knowledge on in-depth descriptions of lived experience with knowledge on self-reported health from standardised generic and disease specific questionnaires, both on the individual and population based level, from the case study approach is likely to:
 - embrace the person-centred and holistic view on the patient perspective of the journey
 - be a stepping-stone for the future challenge of developing a comprehensive patient education program enhancing the quality of care for patients living with AF.

CHAPTER 10. IMPLICATIONS

Results from this dissertation imply aspects, which can facilitate the future challenge and change related to the expanding population of patients living with AF. The chapter will include implications and perspectives for:

- Providing person-centred care in a holistic view
- Developing a comprehensive patient education programme
- Placing the responsibility for the patient journey across sectors
- Suggesting future studies
- Relating to other chronic conditions

10.1. PROVIDING PERSON-CENTRED CARE IN A HOLISTIC VIEW

Providing the patients with a holistic and person-centred care involve listening to individual concerns, giving support, and promoting their own strategies. This awareness is the basis for improving the patient's ability to manage life and is essential for the experience of continuity of care. A variety of factors, not always obvious from healthcare professional's perspective, can be crucial for the patient. The shifting perspective model reflects an example of how dynamic the patient's needs and situations with a chronic condition can be (Paterson 2001). It implies a request for awareness in the role of healthcare professionals to assist and support patients' to identify and understand their perspective on living with a chronic condition. This awareness is essential in order to promote a patient's dignity by minimising the patient's self-blame, and strengthening the feeling of wellbeing. Thereby founded on a mutual respect for the unique patient's situation, preserving dignity, being aware of the meaning of shifting perspectives, promoting autonomy, maintaining responsibility and considering the journey as a process of transition, a person-centred nursing care can be provided.

Planning facilitates a successfully transition (Chick & Meleis 1986), and is thereby likely to uphold and preserve the patients dignity, autonomy and perspective on wellbeing. Planning requires identification of potential problems that may arise. Most patients are willing to take responsibility for their situation. Thus, with the perspective being on illness, and thereby likely to think less rational, combined with holding insufficient knowledge and experiencing an overwhelming responsibility, planning can be challenging. The healthcare provider therefore holds an important role in supporting the patients in planning, and in the perspective of both illness and wellbeing. A healthcare professional's attitude, behaviour, compassion, dialogue and time with the patient is likely to promote the patient's dignity (Chochinov 2007; Chochinov 2013a). Apart from the healthcare professionals' behaviour, hospital environment has also been emphasised for upholding the patients dignity (Baillie 2009). Both the healthcare professionals' attitude and the hospital environment thereby play a central role for the patient's experience of support and care. In healthcare, the importance of professionals considering the patient an equal human being is emphasised (Martinsen 2006a; Martinsen 2006b), and as a human being with feelings that matters (Chochinov 2013b). Being personal engaged in the relation with the patient is thereby essential for being professional. A person-centred care approach thereby request for the healthcare professionals' interest in the patient's situation as a situation of a another human being, and an acknowledgement of the patient being expert in knowledge on own life (Ekman et al. 2014). The healthcare professional's awareness, reflection and openness are central for providing the patient with a feeling of being seen as a human being, and not just a patient. General and typical knowledge on the disease and treatment is important for nursing care, but cannot stand-alone. This knowledge needs to be related to the person's experience of living with the disease. A successful transition can promote the patient wellbeing (both mentally and physically), quality of life and dignity (Chick & Meleis 1986; Schumacher & Meleis 1994). Acknowledging the journey being a transition thus extends this need for time and awareness. Even though patient's participation is important, it is challenging. This time request is in line with a newly published review (Angel & Frederiksen 2015), stating that patient participation request for an adequate time for the patient and the

healthcare professional to build up a relationship and share knowledge. Related to the journey of living with AF it is thereby important to acknowledge the process of transition – that it is an individual process, which takes time, and that the healthcare professionals and the surroundings play a central role for the process to succeed.

10.2. DEVELOPING A COMPREHENSIVE PATIENT EDUCATION PROGRAMME

Despite a person-centred and holistic approach, new options for medical or interventional treatment, and a likely effect from yoga (Lakkireddy et al. 2013), patients living with AF still have an increased risk of death, stroke, heart failure, and hospitalisations (Kirchhof et al. 2013a; Kirchhof et al. 2013b; Freeman et al. 2015; Borg Xuereb et al. 2012). Existing knowledge reports patients experiencing their general practitioner having difficulties dealing with their arrhythmia (Withers et al. 2015), and the patients lack of balanced information related to anticoagulant treatment (Borg Xuereb et al. 2012). The need for early consultation and support from a specialist is thereby emphasised. Valuable support provided by AF clinics after ablation (Withers et al. 2015), and support from specialised healthcare professionals is essential to the patients' process of achieving an accurate understanding of and coping with an arrhythmia (McCabe et al. 2015) are reported. Elaborated from this dissertation, even though the amount of written information is large and standardised, it is not necessarily sufficient. Patients may need more reflective support than expected. The patients might need guidance to prioritise what is most important and translate standardised written information to their own situation. From existing knowledge, patients report that written information, details on support groups, and a specialist arrhythmia nurse are the source points of balanced information (Withers et al. 2015). Direct access to support and frequent follow-up by specialised healthcare professionals, closer collaboration between the hospital and general practice, sharing and upgrading the specific knowledge related to treatment, might be beneficial. Home-based intervention for patients living with AF has recently been suggested and investigated in Australia, but it has not been possible to show significant benefits from this intervention (Stewart et al. 2014). Nurse-led software-supported care for patients

with AF has been tested in the Netherlands (Hendriks et al. 2014; Hendriks et al. 2012). Accordingly, higher levels of AF-related knowledge in the intervention group and lower levels of cardiovascular hospitalisation and cardiovascular mortality are reported. Clinical pathways for direct current conversions have also been reported to be beneficial due to their ability to shorten the patients' waiting time (Zwaan & Umans 2012). By emphasising the weak connection across the boundaries between hospital and general practice, a person-centred and holistic patient education programme must include aspects of this matter, include specific aspects from daily life, family life and work life, patients' self-reported health status, and consider the patient journey as an ongoing process of transition. Group appointments, medical teams oriented towards the individual patient's needs, integrated delivery, and 'focused factories' where patients can go to one location to get all the needed care have been suggested likely to enhance the quality of care (Rein 2007).

Suggestions for a best practice approach for a patient education programme have been provided from the United Kingdom (Lane et al. 2015) and the United States (McCabe 2011). However, development and adjustment of content to the specific organisational and geographical context of a given country, town, and hospital is an ongoing process.

Development and implementation of a comprehensive and adequate patient education programme is complex and call for innovation. Evidence for an innovative process is collected along the process. With reduced resources in today's healthcare sector, innovation is a challenge. Being innovative can be risky and takes courage, and is often challenged by several barriers in the context of the healthcare sector (Herzlinger 2006). Daring to follow ideas and listen to patients, and not being occupied in preliminary knowledge is however according to a newly published paper by Whyte (2016) important for improving nursing care. As suggested by Flyvbjerg (2001) the power of the story illuminating on context of complex issues, as a strength for a case study, can guide the process of decision-making. In-depth descriptions from this case study could thereby provide inspiration and guide an innovative process of developing a comprehensive patient education programme.

10.3. PLACING THE RESPONSIBILITY FOR THE PATIENT JOURNEY ACROSS SECTORS

Organisational managers and leaders hold a responsibility related to providing the holistic and person-centred view on the patient in their journey, and to consider the journey being a process of transition, requesting for appropriate time and awareness. In a Danish context the general practitioner is expected to be the main coordinator of care for their patients (Danske Regioner 2007; Region-Nordjylland et al. 2015). However, the general practitioners limited or lack of role related to coordination of the patient journey has been reported in a qualitative study in the context of Danish cancer patients (Dalsted et al. 2011). Lack of involvement of the general practitioner from other healthcare professionals in the hospital, lack of needed information, general practitioner not being regarded as the coordinator by the patients and lack of close relationship between the general practitioner and the patient, has been suggested as potential factors related to their limited and lack of role. Furthermore, different organisational goals, managements and economic resources account for potentially factors influence the collaboration across organisational sector boundaries. Despite the fact that a cancer patient's journey might be more complex than the journey of a patient living with AF, results from my dissertation support this knowledge. Responsibility in management needs to be more systematic. The management of the responsibility outline for the journey need to be clear for all involved. To provide direction for a responsibility outline call for assistance from the government and the Danish Health Authority.

10.4. SUGGESTING FUTURE STUDIES

Applying the concept of quality of life in a scientific research context, the researchers hold a responsibility for questioning and requesting definitions and arguments. This can be done when writing manuscripts for publication and strive to define and provide strong and solid arguments for applied concepts. In line with the suspected implicit societal agreement raised from Paper 1, critique on the concept of quality of care has been raised by Goldenberg (2012) questioning 'What counts as quality?', reinforcing

the importance of a holistic and person-centred view, both on the concepts of quality of life and quality of care.

In-depth descriptions from an extreme, critical and longitudinal case by involving the best-expected conditions for focusing on the impact of AF, is demonstrated from this dissertation. The journey of living with multi-morbidity might be more complex. Further elaboration of a journey of a patient with multi-morbidity or a patient with asymptomatic AF is likely to broaden the study results.

This study has focused on the patient perspective. Focusing on the importance of the relation between the patient and healthcare professionals could be interesting in a future study.

This dissertation has focused on a local Danish context. Investigating the connection between organisational sector boundaries in other national and international geographically locations, where the connection between sectors are different, could be of interest.

10.5. RELATING TO OTHER CHRONIC CONDITIONS

Awareness of the connection (or missing connection) between organisational sectors, patients shifting perspectives related to illness and wellbeing and the patient journey to be considered an ongoing process of transition is important for the worldview provided in the healthcare system in general and related to other chronic conditions. Healthcare providers role and attitude related to providing a person-centred and individualised care is also illuminated in the context of patients living with diabetes (Phillips 2016) and chronic obstructive pulmonary disease (Ko et al. 2015), long term care (Donnelly & MacEntee 2016) and other chronic conditions (Kogan et al. 2015). These conditions are also serious chronic and complex conditions. They might lead to limitations in the patient's daily life, and are like AF not necessary visible for the healthcare professional, family, colleagues and friends. Person-centred and individualised approaches are provided to minimise the risk of complications to the conditions, to promote patient education and to prevent a relapse, which would require

a readmissions at hospital. The need for upholding dignity, promoting patients autonomy, and overcome a successfully transition are universal human needs, and thus essential for these patient's too.

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LIST OF TABLES AND FIGURES IN THE REVIEW

Table 1. Included papers in the review.

Table 2. Excluded papers in the review.

Table 3. List of papers (1-3) including aims, data sources and designs.

Figure 1. Connection between study context, papers and their contribution to the discussion section.

APPENDICES

Appendix A - Specific search terms applied in the systematic literature research.

Appendix B - Flow chart of inclusion and exclusion of hits.

Appendix C - Example of schedule applied related to review of literature.

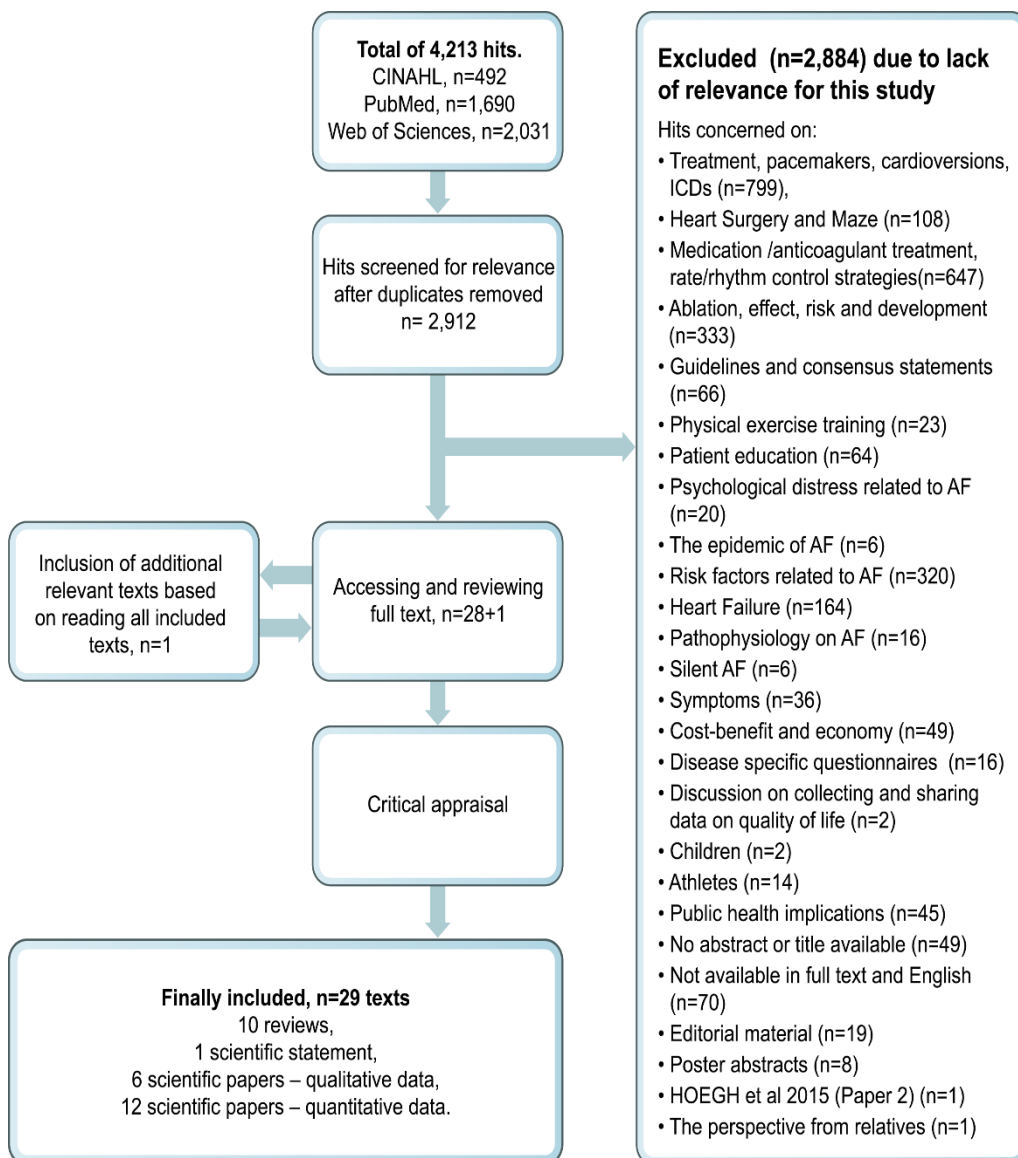
Appendix D - List of the 29 included papers in the literature review.

Appendix A - Specific search terms applied in the systematic literature research.

CINAHL	PubMed	Web of Sciences
MH "Atrial Fibrillation" OR "atrial fibrillation"	Atrial Fibrillation [Mesh] OR "atrial fibrillation"[TW]	TS=(atrial fibrillation)
AND	AND	AND
MH"Quality of life+" OR MH"Patient Compliance+" OR MH "Patient Satisfaction" OR MH "Nurse-Patient Relations" OR MH "Life Experiences+" OR MH "Self Assessment" OR MH " Self Report" OR MH "Health Status+" OR patient* N1 experience* OR patient* N1 perception* OR patient* N1 satisfaction* OR patient* N1 compliance OR patient* N1 view* OR narratives OR lived N1 experience* OR self report* OR self evaluate* OR self rate* OR self assessment* OR health	Quality of life[Mesh] OR Quality of life"[TW] OR Nurse-Patient Relations[Mesh] OR Nurse-Patient Relations[TW] OR lived experience [TW] OR lived experiences [TW] OR Health Status [Mesh] OR health [TW] OR Self report [Mesh] OR Self Report*[TW] OR self- rate* [TW] OR self evaluate* [TW] OR nurse-patient relation[TW] OR Patient Satisfaction[Mesh] OR Patient Satisfaction[Mesh] OR patient satisfaction[TW] OR Patient Compliance[Mesh] OR Patient Compliance[TW] OR patient experience* OR patient view* OR patients experience* OR patient perception* OR patients perception* OR patients view* OR narratives	TS=("quality of life" OR "patient compliance" OR "patient satisfaction" OR "patient experience" OR "patients experiences" OR "patients experience" OR "patient perception" OR "patients perceptions" OR "patients perception" OR "patient view" OR "patients views" OR "patients view" OR "narratives" OR "Nurse patient relation" OR "nurse patient relations" OR lived experience* OR (self rate* OR self assessment* OR self evaluate* OR self report*) AND (health))
492 hits	1690 hits	2031 hits
Hits from 1983 to present	Hits from 1980 to present	Hits from 1988 to present

Search conducted 17 March 2016

Appendix B - Flow chart of inclusion and exclusion of hits.



Appendix C - Example of schedule applied related to review of literature.

	Aim	Design	Result	Contribution/gap	Aspect of the patient perspective	Comments related to CASP
(Engelmann & Pehrson 2003)	Reviewing basic definitions of quality of life applied in research, and to review clinical studies which has assessed quality of life	Review	There is an increasing awareness on quality of life in patients with AF, but data from adequate designed studies are sparse. In general patients' quality of life is impaired, and improved after non-pharmacological interventions.	<p>Important to define quality of life and the dimensions which is assessed. Need for studies with larger sample size, with a control group and considering the heterogeneous population.</p> <p>Suggesting criteria's for planning new studies on quality of life in patients with AF.</p> <p><i>Conceptual definition of quality of life.</i></p> <p><i>Identification of dimension of quality of life.</i></p> <p><i>Specification of rational for choice of measure.</i></p> <p><i>Using at least one generic-instrument.</i></p> <p><i>Using at least one disease- specific instrument.</i></p> <p><i>Selecting an instrument with high and documented reliability and validity</i></p> <p><i>Considering collecting data over time</i></p> <p><i>Ask patients to give an overall rating of their quality of life.</i></p>	The concept of quality of life applied in clinical studies.	<p>Strengths Provide guidance for planning further studies. Emphasis on an appropriate study design</p> <p>Limitations No information on search strategy. More than one specific aim.</p>

Appendix D - List of the 29 included papers in the literature review.

	Aim	Design	Key result	Comments
(Jenkins & Bubien 1996)	To review current literature related to quality of life in patients living with AF.	Literature review	Future studies need to provide quantification of impact of various treatments, quality of life in patients with various symptom burden, predictors for quality of life, the relationship between quality of life and adherence to treatment and mortality.	This is the earliest located contribution to the discussions on the patient perspective of AF. The study emphasise the importance of consider the multi-dimensions related to the concept of quality of life. Lack of abstract and a clearly description of structure, aim and method for how the review is provided. Contribute to: 1, 2 and 3*
(Lüderitz et al. 2000)	To define quality of life, and provide suggestions for addressing quality of life. To review current literature and discuss with new clinical trials, assessing quality of life in patients with AF.	Literature review	A call for further knowledge on the patient perspective of AF. Quality of life is likely to be important for gaining information on the patient perspective, however rigorous and practical approaches is needed to facilitate a comprehensive understanding.	The paper contributes with information on missing control group and low sample size in previous studies. Furthermore, previous studies are mostly performed on symptomatic patients. A large variation of assessment tools makes it hard to compare study results. The importance of reliability and validity related to the diversity of the concept of quality of life is thereby emphasised. The review lack of clear search strategy and how the studies are located. The aim be more specific. Contribute to: 1*
(Engelmann & Pehkonen 2003)	To review basic definitions of the concept of quality of life and clinical studies addressing the concept in research related to patients living with AF.	Literature review	There is an increasing awareness on quality of life in patients with AF, but data from adequate designed studies are sparse. In general, the patient's quality of life is impaired, and improved after non-pharmacological interventions. When planning a new study on the concept of quality of life.	From the paper the importance of defining quality of life and the dimensions which is assessed is emphasised. Studies with larger sample size and control groups, considering the heterogeneous population of patients with AF are needed. The paper provides guidance for planning further studies, with emphasis on an appropriate study design. The study lack information on search strategy. The aim could be more specified. Contribute to: 1, 2 and 3*
(Gronefeld & Hohnloser 2003)	To review current data on assessment of the concept of quality of life in patients with AF, discuss definitions, usefulness of clinical patterns and classification of AF for the concept of quality of life, and provide definitions and suggestions for further clinical research.	Literature review	A combination of disease-specific and generic instruments is recommended. It is important to differentiate between symptoms, health status and quality of life. Importance of explicating reasons for using the specific instrument in order to prevent misinterpretation of results.	Assessment of quality of life in patients with AF is important. Emphasise the need for elaborating on strengths and limitations related to the concept. No information on search strategy, inclusion and exclusion provided. Contribute to: 1*
(Schron & Jenkins 2005)	To summarise what is known about quality of life in older patients with AF.	Literature review	Specifying rational for a study, and include more than one assessment when assessing the concept of quality of life is important. Information on other life events than what can be captured from a standardised instrument is needed.	Need for studies with a longitudinal design, and studies focusing on other life events than health issues. No information on search strategy, inclusion and exclusion in the review. Contribute to: 1 and 3*
(Thrall et al. 2006)	To examine quality of life in patients with AF. Systematically evaluate the effect of rate-rhythm control strategies for patients living with AF, and provide recommendations for design of future studies.	Systematic literature review	Impaired quality of life in patients with AF is suggested. However, the existing studies are compromised with methodical weaknesses. Statistical powered studies are needed in order to clarify the association between AF and quality of life. Need for larger trials, also on a more general population of patients.	A well written systematic review. Criteria for inclusion and exclusion and search strategy are accurate presented. Contribute to: 2 and 3*
(Lane & Lip 2009)	To review current knowledge on quality of life in older patients with AF.	Literature review	One third of patients experiences levels of depression and anxiety persisting in 6 months, in line with the level of post-myocardial infarction patients. Quality of life is poorer among women compared with men.	The paper contribute with information on lack of focus on the personal sequel of AF, and how such sequelae affect the patient's quality of life. Need to study on gender difference and how AF affect the person's life. No information on search strategy, inclusion and exclusion of research provided. Contribute to: 1, 2 and 3*
(Aliot et al. 2014)	To review generic and specialised instruments of measuring quality of life in the context of AF patients.	Review	Related to the advancement of therapies and treatment guidelines, development and validation of new quality of life assessment tools has a central role.	Providing suggestions for how to asses and improve quality of life in AF patients, from questionnaires, based on generic tools, AF specific quality of life scales and AF specific symptom scales. No description of search strategy for locating existing tools from the literature. Contribute to: 1 and 2

(Zhang et al. 2015)	To evaluate the impact of AF on health-related quality of life in older patients (>65 years), identify effects of treatment interventions on health-related quality of life, and identify if age can predict health-related quality of life in this older group.	Literature review	Older patients with AF had significantly impaired both mentally and physically components of health-related quality of life. Being old, female or having a severe symptom burden resulted in poorer physical health-related quality of life.	Use of a disease-specific instrument is important, but quantitative measures alone do not tell the full story of the patient perspective. Emphasise the need for comparing with a control group from the general population. A clear description of search strategy, inclusion and exclusion provided, however, only published studies between 2003 and 2013 are included. Contribute to: 2 and 3
(Mark 2016)	To examine the use of health-related quality of life as outcome in current clinical cardiovascular research.	Literature review	A large gap between what current used measurements parameters can provide and the data needed in order to incorporate the patients' voice into therapeutically decision-making. Strengths and limitations related to large randomised trials are emphasised.	Lack of familiarity with quality of life measures and their interpretations and unrealistic expectations of what information they can provide are suggested obstacles to their use. Concerns overall clinical cardiovascular research and not only the context of patients living with AF, illustrating that the concerns related to the concept of quality of life is not only relevant for the context of patients living with AF. Contribute to: 1, 2 and 3*
(Rumsfeld et al. 2013)	To review and advocate for patient reported health status as a measure of cardiovascular health, and to define and describe key aspects of the patients health status.	Scientific statement	Research is needed in order to understand determinants of patient's health status, the effect of interventions and the most effective strategies of including the health status measure into clinical practise and disease surveillance.	The statement from the American Heart Association is concerned on cardiovascular health and not only on health-related to living with AF. The statement advocated for broader inclusion of patient's self-reported health status, as a key measure of cardiovascular health in clinical research. Contribute to: 2*
(McCabe et al. 2011)	To describe how patients experience to live with recurrent symptomatic AF.	Qualitative descriptive design	Patients experience delay in diagnosis, minimising of concerns, inadequate self-management counselling, lack of emotional support, and distress associated with unpredictable symptoms, requiring attention from researchers and clinicians. Interventions for patients to improve recognition of symptoms, and an educational program for patients and families with AF are needed.	Data were collected only one point in time. Participants were a selected group because they had no severe comorbidity. Contribute to: 3*
(Ekblad et al. 2012)	To explore critical incidents in which patients experience how AF affects their wellbeing, and actions applied to manage and prevent another critical incidents.	Qualitative descriptive design	The patient's personal experiences are the base for actions on AF. The patients experience discomfort and limitations in daily life, and worry about the future. Actions related to these experiences involve being in a state of readiness, adoption of the condition and a need for healthcare.	Based on interviews from critical incidents techniques with 25 patients (16 men and 9 women), the study focus on how patients manage life with AF. The paper contributes with emphasis on the importance of identifying and giving importance to how the patient's daily life is affected. Furthermore, that future research needs to involve how AF affects the patient's next of kin. Data were only collected at one point in time. Contribute to: 3*
(Dalteg et al. 2014)	To explore couples main concerns and management strategies in the situation in their relationship with one of them afflicted by AF.	Grounded theory design	Uncertainty is a main concern, related to cause of AF and apprehension on AF episodes. The couples share their concerns implicit and explicit. They collaborate to find resemblance or keeping distance with tacit understanding. Neither type of strategy eliminates couples feelings of uncertainty.	Emphasise the need for focusing not only on the patient but on the patient as a person involved in social relations. Interviewing patient and partner together (with 12 couples) and alone in the follow-up with two patients and two partners. The study provides knowledge on strategies for couples and not individual patients. The paper reveals limited descriptions of the role as researcher, and it is unknown if more than one investigator were included in the analysis process. Contribute to: 3*
(McCabe et al. 2015)	To describe patients experiences from symptom onset to initial treatment for AF.	Qualitative descriptive design	Importance of influence of patient-provider interactions during diagnostic and early treatment phase. The patients need cues from healthcare professionals in order to recognise signs and symptoms. Fear and uncertainty reduced when providers took their time, and provided the patients with knowledge and support. Negative experiences occurred when healthcare providers diminished and doubted the patients concerns. Healthcare providers need to communicate effectively.	By participating in interviews based on open-ended questions, 20 females and 21 males diagnosed and previously admitted due to AF participated in the study. Qualitative content analysis used for analysing data. There is a need for evidence-based interventions to address patients' response on life with AF. The study focus on patients with symptoms on AF. Further studies on patients with asymptomatic AF are needed. Need for focusing on ethnic and cultural diversity. Data are collected only one point in time, and there is a risk of 'recall experiences', because the time from admission to interview was like up to a year. Lack of discussion of data saturation. Contribute to: 3*
(Withers et al. 2015)	To conduct a qualitative cross-sectional survey to understand patients perspective of how cardiac arrhythmias affect their daily lives.	Qualitative cross-sectional survey	Symptoms of the arrhythmia caused considerable problems and impact on quality of life, as anxiety, and likewise impact on work and social life. Lack of support and information and poor understanding of the illness from relatives and healthcare professionals.	25 patients participated in cognitive interviews. The study provides knowledge on the impact on family life and work life when living with AF. AF does not only affect the patients but also the once close to them. This need to be further explored. Common themes identified using content analysis. Mix in the terminology of qualitative and quantitative approaches reveal question of if it is a pure qualitative design. This study is phase 1 of a larger study aiming to develop a disease specific patient reported outcome toll for patients with AF. Another limitation is the double aim, both to

				test a questionnaire and to determine factors of importance for patients. 20 interviews proposed to be sufficient for data saturation, but could less be enough? Contribute to: 3*
(Altioek et al. 2015)	To determine perceptions of patients living with AF, regarding the disease, their feelings, thoughts and wishes, in order to elaborate on patients coping strategies.	Semi-structured qualitative interviews	Major limitations in daily life and social life due to symptoms from AF and warfarin use. The patients are anxious and fear to be paralysed and depended on others. Feeling burnout and experience financial challenges due to frequent hospital visits and visits in general practice. The patients need individualised training and counselling. Appropriate health appointment and monitoring systems needed in order to reduce problems associated with frequent follow-up. Patients neglects to go to hospital due to long exhausting waiting time.	32 patients participated in the study. Data was analysed from a continuous comparative method by Colaizzi (phenomenological methodology). The need for employing individual positive coping strategies, insecurity related to frequent change in healthcare provider, impact on sexual life are being emphasised. Assessing the number of participants mentioning the themes from the analysis – focus on numbers less on descriptions, which is likely to question the phenomenological methodology. The discussion of generalisability lack of strengths related to qualitative studies. Data are translated from Turkish to English. Only 66 pages of transcripts from interviews with 32 patients. Data only collected at one point in time. Contribute to: 3*
(Dorian et al.	To assess the impact of intermittent AF on health-related quality of life.	Cross-sectional design	Impaired quality of life in patients with intermittent AF, at the same level as in patients with structural heart disease. Quality of life is not dependent on the objective measures of disease severity usually employed.	Based on SF-36 and symptoms, this is the earliest study contributing information on impaired health status in patients with AF. 152 AF patients participated in the study. Low sample size was therefore a challenge. Stratification on gender was therefore not possible. A standard deviation of 0.5 was defined as a significant change in the scales of SF-36. No summary scores from SF-36 are applied. Does not consider potential confounding from comorbidity. Contribute to: 2*
(van den Berg et al.	To determine the impact of paroxysmal AF on quality of life. To determine the predictors of quality of life, especially the role of symptoms and autonomic function.	Cross-sectional design	Paroxysmal AF causes significant impaired quality of life for patients compared to controllers in four of the scales in SF-36: physical role function, emotional role function, vitality and general health. Symptoms and autonomic function are important predictors of quality of life in this group of patients.	Study outcomes are SF-36 and symptoms. The study has a low sample size of 73 participants and 180 controllers. The paper lack discussion of what is a minimal clinical difference. Contribute to: 2*
(Kang & Bahler	To describe health-related quality of life and to examine the impact on seriousness of illness on health-related quality of life, for patients being newly diagnosed with AF.	Cross-sectional design	An indication of health-related quality of life being significantly impaired in patients newly diagnosed with AF, as compared to the US population norms. Subjective seriousness of illness has a pivotal impact on health-related quality of life in AF.	The descriptive correlational and cross-sectional study includes 81 subjects. The study is challenged by a low sample size. The study emphasise the need for studies with high statistical power. Contribute to: 2*
(Maryniak et al. 2006)	To learn about circumstances related to new onset of paroxysmal AF. To assess how these situations contribute to psychological importance and the influence on the patient's quality of life.	Cross-sectional design	Objective indicators, disease duration and comorbidity does not affect the patient's subjective assessment of quality of life. Episodes with onset of AF and disorganisation of activities and psychological value significantly influence patient's quality of life. Further knowledge on circumstances related to new onsets of AF needed.	76 AF patients referend to ablation, report a psychological evaluation, SF-36, physical examination. The study challenged by low sample size. Looking at statistical significant correlations, and lack discussion of clinical important differences. Contribute to: 2*
(Ong et al. 2006)	To investigate gender differences, depression and health-related quality of life in patients with AF.	Cross-sectional design	Among AF patients, female patients report lower physical quality of life, relative to male patients. Self-reported depression may mediate this relationship. More research, also longitudinal studies needed in order to determine the relationship with depression on physical quality of life, especially considering the burden from AF on women.	With only 93 participants (32 female and 61 male patients), the study was challenged with a low sample size. Contribute to: 2*
(Dagres et al. 2007)	To investigate gender-related differences of health status for patients with AF in Europe.	Cross-sectional design	Higher age and lower quality of life in women, compared to men. Women had more comorbidity (heart failure). Women had higher chance of stroke, and were treated with less rhythm control than men in case of asymptomatic AF.	The study is part of a larger European survey study based on the generic tool EQ-5D, and can thereby provide knowledge from 5333 participants. Lack of comparison to the general population. Contribute to: 2*
(Ariansena et al. 2009)	To compare 75-year old patients with and without permanent AF, related to health-related quality of life and exercise capacity.	Cross-sectional design	Older patients with permanent AF had higher odds for poor exercise capacity and poor physical health status compared with subjects in sinus rhythm.	With 27 subjects with permanent AF and 71 in sinus rhythm, the study had a low sample size. Contribute to: 2*

(Perret-Guillaume et al. 2010)	To investigate health-related quality of life in elderly (more than 65 years) inpatients with AF, compared with age matched controllers.	Cross-sectional study	Health-related quality of life mainly altered in the 'psychological' domains. Future research needed to determine the most appropriate assessment tool to assess the impact from AF on health-related quality of life. It is important to address lower health-related quality of life, and to find new ways to improve it, and better taking into account of other comorbidities, and to improve social and family support, and a better follow-up in ambulatory practice.	Health- related quality of life assessed from SF-36 and Duke Health Profile. With 41 AF patients (14 women and 27 men) and 123 matched controllers free of cardiac arrhythmias (matched on age, sex and hospital department), the study lack of statistical power due to low sample size. The study furthermore lack discussion related to what is a minimal clinical important difference in SF-36. The study had a low sample size. Stratification on gender was therefore not possible. Current disorders and treatment could be confounding factors. Contribute to: 2*
(Bohnen et al. 2011)	To determine the effect of AF on quality of life in patients and spouses.	Cross-sectional design	AF has a similar impact on quality of life on spouses and patients. Improvement strategies for patients living with AF should therefore consider spouses.	Important to account for the impact of AF on spouses and significant others. A five-scale questionnaire on quality of life (daily activity, work life, sex life, physical activity, psychological wellbeing and social activity) was provided to 568 participants (411 patients and 129 spouses). A non-validated questionnaire applied in the study to assess quality of life. Data collected at one point in time. Contribute to: 2*
(Roalife et al. 2012)	To compare quality of life of those in AF aged >75-year with the general population.	Cross-sectional design	Comorbidity was associated with reduced health status score. Physical component of SF-12 was more sensitive than the mental component score on capturing the impact on health status. In the absence of comorbidity, AF has little impact on generic health status, in elderly non-actually ill population.	The study had a large sample size (n=1762). EQ-5D and SF-12 self-administrated of patients to provide information on self-reported health. Cardiovascular comorbidities and drugs used to calculate a proxy for comorbidity. The study results emphasise the need for statistical powerful studies, also representing women and elderly participants. Contribute to: 2*
(Segi et al. 2012)	To describe the success of either strategy or the impact of control on symptomatic status of patients with AF.	Cross-sectional design	AF control is not optimal. Control seems to be associated with fewer symptoms and better quality of life, but even patients with controlled AF have frequent symptoms, functional impairment, altered quality of life and cardiovascular events. Future treatment need to focus on improving control, and to minimise functional and quality of life burden for the individual patient. Heart rate control was only adequate at rest, not at exercise.	The study is an international study providing data from a diverse cohort of 10,523 (9,665) participants. Symptoms are being assessed from - EHRA score, and quality of life from EQ-5D. Contemporary, intentional, representative sources of information on patients' with the whole spectrum of AF needed. The aim is to elaborate on the impact of control. The study is relevant due to results on self-reported health (quality of life from EQ-5D), on the large sample of patients with AF. Contribute to: 2*
(Lioni et al. 2014)	To evaluate the difference in quality of life and psychological stress parameters among patients with paroxysmal AF and common forms of atrioventricular re-entry supraventricular tachycardia.	Cross-sectional design	Patients with AF report significantly impaired quality of life and higher level of anxiety compared to patients with other supraventricular tachycardia.	With 106 participants including 54 AF patients, the study had a low sample size. Data collected only before the ablation procedure. AF patients were older, and analysis not stratified on gender. Provide no reflection on a minimal clinical important difference in score. Contribute to: 2*

***Contribution**

1: Theme no. 1 - Quality of life 2: Theme no. 2 - Self-reported health status 3: Theme no. 3 - Lived experience

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