The Professional Support Needs and Experiences of Patients with Atrial Fibrillation: A Mixed Methods Study

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Abstract

There are in excess of one million people across the UK people living with atrial fibrillation (AF), a long term condition that can lead to stroke and other complications, costing the NHS over £2,200 million per year. However little is known about the experience of living with AF and what patients' perceptions are of the support they receive from health professionals.

In order to ensure that patients have the best possible experience of care, healthcare professionals need to have an understanding of how patients view their condition and the type of support they would like to receive from the professionals involved in their care. Although there has been a significant amount of work investigating social support for people with health conditions, there has been little work exploring support provided by healthcare professionals, defined in this study as professional support.

This study aimed to investigate and assess the professional support needs of people with AF to develop knowledge and understanding in this field. A theoretical framework for professional support was developed based on the tri-dimensional model of social support and was used to direct the research.

Using an exploratory sequential design, a two phase mixed methods study was undertaken. Initially, qualitative interviews were undertaken with patients recruited from outpatient arrhythmia clinics at one National Health Service (NHS) hospital and identified from the perspective of the patient how, when and where healthcare professionals did/did not provide support. Key components of emotional, informational and tangible professional support were identified from thematic analysis of the interview data and used to inform the development of a quantitative questionnaire. Physical activity, exercise and the impact of AF on activity levels were identified by participants as important and so were also included.

The quantitative online questionnaire was completed by patient members of the Atrial Fibrillation Association (AFA). To examine relationships between variables, statistical analyses were performed using Fisher's exact test and indicated that people with AF had a range of emotional, informational and tangible professional support needs. Different subgroups of people with AF had different professional support needs: People with more severe symptoms needed more emotional support as well as more tangible support and people with paroxysmal AF needed more

informational support. People undergoing ablation as treatment for their AF had specific informational and emotional needs for support.

AF played a significant part in the lives of people with AF by modifying activities of daily living and shaping physical activity behaviour and choice of activities. People with AF therefore needed professional support in maintaining and/or increasing their levels of activity.

Considering the specificity of professional support, GPs, cardiologists and arrhythmia nurse specialists were identified as most supportive, with GPs and cardiologists also considered as the least helpful at providing support, indicating a variation in professional support.

The findings from this study contribute to the limited body of knowledge describing the experience of living with AF and provide healthcare professionals with a unique understanding of how best to provide professional support. The tri-dimensional model provides detailed knowledge of the components of informational, emotional and tangible support that people with AF would like to receive from the healthcare professionals involved in their care. The findings indicate there are differing support needs for different subsets of people with AF demonstrating a need for individualised professional support.

The theoretical framework for professional support used in this study provides a model that could be used in future research studies to identify the types of professional support required by patients and to identify subgroups of patients who may require additional professional support. By accurately identifying the needs of patients, this will ensure that healthcare professionals are able to deliver effective patient centred services, leading to an improved patient experience and the delivery of high quality patient care.

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Matthew: Your courage to deal with life's challenges has helped me keep on going, even when things got tough

Steve: Words can't really thank you for everything you have said and done over the time it has taken to complete this research and beyond. Quite simply, you are the best.

Contents

Index of Tables

Index of Figures

Abbreviations

A&E	accident and emergency
ACC	Arrhythmia Care Co-ordinator
AF	atrial fibrillation
AFA	Atrial Fibrillation Association
ANS	Arrhythmia Nurse Specialist
BHF	British Heart Foundation
CABG	coronary artery bypass graft
CAQDAS	Computer aided qualitative data analysis software
CCNAP	Council on Cardiovascular Nursing and Allied Professions
CHD	coronary heart disease
CMO	Chief Medical Officer
CPP	chronic pelvic pain
CR	Cardiac rehabilitation
CRIPACC	Centre for Research in Primary and Community Care
DH	Department of Health
DHRes	Doctorate in Health Research
ECG	Electrocardiogram
EHRA	European Heart Rhythm Association
ER	emergency room
ESC	European Society of Cardiology
FAB	Fear Avoidance Beliefs
FABQ	Fear Avoidance Beliefs Questionnaire
FABQpa	Fear Avoidance Beliefs Questionnaire physical activity subscale
GP	General Practitioner
GPPAQ	General Practice Physical Activity Questionnaire
H&EA	Hobbies and everyday activities
HCP	health care professional
HRC	Heart Rhythm Congress
HR-QoL	Health related quality of life
IBS	Irritable bowel syndrome
ICD	Implantable cardioverter defibrillator

INR	International Normalised Ratio
INRC	International Nursing Research Conference
LTC	long term condition
MI	myocardial infarction
MM	mixed methods
MMR	mixed methods research
MSc	Master of Science
NCGC	National Clinical Guideline Centre
NCPC	National Council for Palliative Care
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
PA/E	physical activity/exercise
PAF	Paroxysmal Atrial Fibrillation
PAI	Physical Activity Index
QUAL	qualitative
QUANT	quantitative
REC	Research Ethics Committee
SF-36	Medical Outcomes Study Short Form- 36
SPSS	IBM SPSS Statistics v21
SSN	Social Support from Nurses
TIA	Transient Ischaemic Attack
UH	University of Hertfordshire
UK	United Kingdom
WHO	World Health Organisation

1 Introduction

There are in excess of one million people across the UK people living with atrial fibrillation (AF) with this figure increasing and likely to affect 2.5-3% of the population by 2050 (Savelieva and Camm 2008). Reviews of evidence show that people with AF report diminished health related quality of life (Jenkins and Bubien 1996 and Thrall et al 2006) but research detailing the lived experience of people with AF has been described as "extremely limited" (McCabe et al 2011, p. 336).

AF is a long term condition that can lead to stroke and other complications (Wolf et al 1991) with a cost to the National Health Service (NHS) of over £2,200 million per year (Atrial Fibrillation Association 2010). However despite this significant demand on the NHS, little is known about the perceptions of people with AF regarding their treatment, including the support they receive from healthcare professionals involved in their care.

The focus of this study is to investigate the professional support needs of people with atrial fibrillation (AF). In order to ensure that patients have the best possible experience of care, it is clear that healthcare professionals need to have an understanding of how patients experience their condition and of their needs and preferences to allow them to individualise the care and support they provide.

1.1 Patient experience

Despite advances in medicines and technology to treat conditions and an associated improved survival rate (NHS England, 2013), recent high profile cases such as Mid Staffordshire suggest that there is still room for improvement in the quality of healthcare people receive notably regarding patient experience. Over recent years, increased emphasis has been placed on the importance of the experience of the patient and how to ameliorate this where possible in an effort to improve quality of health care. In his review of the National Health Service (NHS), Lord Darzi described patient experience as one of the three core elements of quality in the NHS together with patient safety and clinical effectiveness (Department of Health, 2008).

The National Institute for Health and Care Excellence (NICE[1]) also highlighted that "*High-quality care should be clinically effective, safe and be provided in a way that ensures the patient has the best possible experience of care*" (NICE 2012a, p.7) with the NHS Confederation (2010) reporting the benefits of delivering a high quality patient experience as improving outcomes, indicating poor care, reducing costs and informing choice. National Clinical Guideline Centre (NCGC) (2012) recognise that patient experience can be divided into two parts 1) the patient's experience of their symptoms or disorder and 2) experience of the care the patient received from health services.

A similar view of quality was proposed by Berwick in 2009 "*Patient-centeredness is a dimension of health care quality in its own right, not just because of its connection with other desired aims, like safety and effectiveness*" (p.w555). Gerteis et al (1993) used an iterative approach involving focus groups, telephone interviews and a national survey to develop a framework of seven dimensions of patient centred care. These were as follows:

1. Respect for patients values, preferences and expressed needs

2. Coordination and integration of care

3. Information, communication and education

4. Physical comfort

5. Emotional support and alleviation of fear and anxiety

6. Involvement of family and friends

7. Transition and continuity of care

In 2007, Shaller reported that the Picker Institute refined this framework to propose eight dimensions of patient-centred care: the seven proposed by Gerteis et al (1993) with the addition of an eighth dimension, 'access to care' (Shaller, 2007, p.36). NCGC (2012) reviewed these frameworks to see if they provided a structure to

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[1] The National Institute for Health and Care Excellence was first named the National Institute for Clinical Excellence when established in 1999. Then in 2005 it became the National Institute for Health and Clinical Excellence before being given its current name in 2013. The abbreviation NICE will be used in this document as an abbreviation for all three names.

consider patient experience and their thematic analysis identified key generic themes: patient as active participant, responsiveness of services- an individualised approach, lived experience, continuity of care and relationships, communication, information and support.

These narrative descriptions of these key themes (based on the reviewed literature) highlight the importance of being seen as a "person within the healthcare system" and of being recognised as an individual. The role of patients as "potential active participants in their healthcare" and the need to recognise that "individuals are living with their condition and experiencing it in a unique way" is also highlighted together with the need to provide tailored information to enable self-care and active participation in healthcare. The fact that individuals will have different preferences for support and that there is a need for emotional and practical support are also acknowledged (NCGC, 2012 p.39 – 40).

Therefore, in order to ensure that patients have the best possible experience of care, it is clear that healthcare professionals need to have an understanding of how patients experience their condition and of their needs and preferences to allow them to individualise the care and support they provide.

This study places the experience of patients at its heart to identify from the perspective of the patient how healthcare professionals can support patients with atrial fibrillation. Identifying the needs of this group of patients will enable healthcare professionals to deliver effective patient centred services; failing to identify and address such needs will mean that patients not have the best possible experience of care and will be receiving suboptimal care from their healthcare professionals.

1.2 Research Purpose

The study aims to identify and assess the professional support needs of people with AF. The study objectives are:

- To identify and examine the professional support needs of patients with atrial fibrillation through qualitative interviews

- To use the findings from the qualitative phase to inform and influence the development of a patient-centred questionnaire regarding professional support needs of people with AF

- To conduct a quantitative survey of people with AF to:

  o Establish professional support needs across a population of people with AF

  o Consider differences in professional support needs in relation to:

    ▪ *Symptom severity of AF*

    ▪ *Symptom frequency of AF*

    ▪ *Classification of AF*

    ▪ *Treatment strategy for AF*

    ▪ *and duration of AF*

  o Investigate beliefs regarding physical activity and AF and the impact of AF on physical activity behaviour

- To contribute to the evidence base on professional support needs of people with AF

- To contribute to improving patient care through guiding care planning for people with AF

1.3   Personal reflective statement

My interest in studying the experience of patients with atrial fibrillation arose from sharing the experiences of family members with AF who felt they hadn't received the support and advice they needed to manage their condition. Hearing their narratives made me curious to see if this was an experience common to all patients with AF. As a clinician turned manager working in the NHS with a responsibility for services for patients with arrhythmias, it also felt important that the study should be applicable to my professional practice and provide a solution as to how any gaps could be addressed to improve patient experience and quality of care.

Given my previous research experience, my initial plan was to carry out a quantitative study based on knowledge gained from published evidence and clinical experts to design a questionnaire to identify the needs of people with AF. However, through the learning I undertook as part of the Doctorate in Health Research (DHRes) combined with my family's experiences of living with AF, it became clear to me that such an approach was far removed from the patient centred approach which I believed should underpin the care and delivery of health care. Therefore I had to adopt an approach that would put the patient voice at the heart of my research and so I chose a mixed methods approach to ensure that the experience of patients guided and informed the study. For a more detailed reflexive account, see the section entitled "Reflexivity" (page 178).

1.4   The Professional Doctorate

This study was conducted as part of the Doctorate in Health Research (DHRes) at the University of Hertfordshire (UH), which is a professional doctorate aiming to "*explore the interaction of theory and practice in research within the health professions*" (Centre for Research in Primary and Community Care (CRIPACC) 2013, p.7).

In reviewing professional doctorates in the UK, Brown and Cooke (2010, p.6) describe professional doctorates as "*purposefully adapted to suit doctoral level study in a professional field rather than academia per se*" and therefore attracting students "*who are working in a professional environment to further develop their skills, knowledge and professional practice*" (Brown and Cooke, 2010, p.6). Brown and Cooke add that the professional doctorate has "*elements of taught provision and is normally delivered to cohorts of students rather than for the individual which remains the case for the traditional PhD*" (2010, p.6).

The DHRes is a part time programme and has two components: a taught programme of core and optional guided learning and a "substantial piece of professionally focused research" (CRIPACC, 2013, p8). It consists of three phases of study, with each phase involving an assessment panel to assess suitability to progress to the next phase. My first two phases consisted of core and guided learning for which I submitted evaluations which facilitated the development of my research skills and also contributed to the development of the research proposal for this study. It has

also developed skills and knowledge which I have applied to my ongoing professional role; those of critical appraisal being of particular relevance. Appendix A: Personal Development Account contains a more detailed reflection of my experience together with supporting evidence showing the development of my research skills, knowledge and expertise throughout my time completing the DHRes.

1.5 Structure of the dissertation

Following this introduction, this dissertation details the in-depth research undertaken as part of the DHRes. It is divided into ten further chapters set out as below.

Chapter Two gives a broad overview of atrial fibrillation, the clinical area addressed within the dissertation, so that the underlying issues pertinent to professional support are defined. AF is described and clinical features of the condition are explored from the patient perspective.

Chapter Three provides an overview of the literature relating to professional support as well as other areas that may inform work in this area. Social support, supportive care and self-care/self-management are reviewed and a framework for professional support is proposed.

Chapter Four outlines the methodology for the overall study, exploring the issue of mixed methods research. It is followed by Chapter Five which provides detail of the initial qualitative phase of the study including methods, ethical issues, recruitment, data collection and data analysis.

The findings from the qualitative phase are described in Chapter Six with Chapter Seven linking the qualitative phase to the quantitative phase. Chapter Eight details how the findings informed the development of the quantitative phase of the study. Development of the questionnaire together with issues regarding methods, ethical considerations, piloting the questionnaire, data collection and data analysis are included in this chapter. The results from the quantitative phase are then detailed in Chapter Nine.

Chapter Ten deals with issues of quality as they apply to mixed methods research and how they have been addressed in this study. Limitations of the study are also included in this chapter.

Chapter Eleven discusses the evidence from this study in the context of the work of other authors. The framework of professional support is revisited and discussed in more detail in light of the findings from this study.

Finally Chapter Twelve draws conclusions from this study, including implications for professional practice, future research and policy.

2   Atrial Fibrillation

2.1   Introduction

The purpose of this chapter is to explain atrial fibrillation, the clinical area covered in this study, in order to provide understanding for subsequent chapters. This chapter will describe atrial fibrillation (AF) and its impact on people who experience it, to set the scene for discussing the support needs of this patient group. It does not provide detailed descriptions of treatment modalities for this condition, instead focusing on the effect of the condition on people who experience it, in line with the overall themes of patient experience which underpin this study.

AF is the most common cardiac arrhythmia[2] in the United Kingdom, affecting approximately 1 in 100 of the population (Stewart et al 2004), which increases with age to 4 in 100 in the over 65s and 9 in 100 in the over 80s (National Collaborating Centre for Chronic Conditions 2006, page 4). Savelieva and Camm (2008, p.55) describe AF as an "epidemic", predicting that it is likely to affect 2.5-3% of the population by 2050.

From a patient perspective, many patients with AF have no symptoms and are therefore unaware of their abnormal heart rhythm or have vague non-specific symptoms (National Collaborating Centre for Chronic Conditions 2006). However, for patients with symptoms, these range from the most common symptom of palpitations, (an uncomfortable awareness of the rapid and irregular heartbeat) to other symptoms of atrial fibrillation caused by the diminished delivery of blood to the body, including dizziness, fainting, weakness, fatigue, shortness of breath, and angina (chest pain due to reduced blood flow to the heart muscles) (Walker et al. 1990; Yee and Rozewicz 2003).

AF is classified as initial event, paroxysmal (intermittent, lasting more than 48 hours but less than seven days and self-terminating), persistent (not self-terminating, lasting more than seven days) or permanent (not terminated or terminated and relapsed) (Levy et al. 2003). Silent AF (asymptomatic AF) may exist as any of the above types and may only be discovered through an AF-related complication such

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[2] An arrhythmia is an abnormality of the heart's rhythm, either caused by an inherited problem or by an acquired condition that disturbs the electrical impulses which regulate the heart. (Department of Health 2005a, p.3)

as ischaemic stroke or may be diagnosed by an opportunistic electrocardiogram (ECG) (Camm 2010).

Although initially perceived as benign, AF is now recognised as a "life-complicating chronic illness" (McCabe 2010) with patients at risk of increased mortality and morbidity, including a five-fold increased risk of stroke (Wolf et al 1991). AF has been described as a "challenge for the clinician" (Levy et al 2003, p.119) and the effects of AF described as "chronic and significant, for both patients and the health system at large" (Yee and Rozewicz 2003, p.27).

2.2   Management of AF

Due to the heterogeneous clinical presentation of AF, its management is complex and depends on a variety of factors including the type and duration of AF, the impact of symptoms, underlying disease and treatment goals (Banner 2008). The two main treatment strategies are rate control and rhythm control combined with the important factor of preventing antithromboembolic complications (National Collaborating Centre for Chronic Conditions 2006.). Treatment may include cardioversion (pharmacological by the use of drugs to restore and maintain sinus rhythm or electrical through the administration of a direct current electric shock to restore sinus rhythm), ventricular rate control strategy (aiming to reduce the rapid heart rate often found in AF patients) or increasingly electrophysiological interventions such as the maze procedure and catheter ablation. Recent guidelines for the management of AF report that "*the technique of ablation has continued to evolve*" with the accumulated evidence demonstrating success rates of 90% in cases of paraoxysmal AF (PAF) and 80% in cases of persistent AF (Fuster et al. 2006). However, despite the apparent success of this new treatment modality, there is still limited evidence re the long-term benefit of this technique as most studies have only followed patients up for a year.

2.3   AF and Quality of Life

Although a range of treatment strategies for AF exist, success is variable and PAF and persistent AF have a pronounced tendency to recur (Fuster et al 2006). Due to the chronic nature of AF, treatment and management is often life-long with few interventions having an impact on mortality and morbidity and therefore treatment is

often aimed at symptom control and improvement of quality of life (Arribas et al 2010 p364). Smith et al (2010) highlight quality of life as an "important treatment outcome" for this group of patients.

Despite this, a review of quality of life studies in patients with AF in 1996 (Jenkins and Bubien 1996, p.598) identified that *"the perspective of the patient has largely been undocumented"* and a further review (Thrall et al 2006, p.448.e1) a decade later, found that this was still the position:

> *"Although the epidemiology, clinical consequences and costs of atrial fibrillation have been subject to considerable study, less attention has been paid to patient-related issues, such as quality of life"*

In the first review, Jenkins and Bubien (1996) found that most studies looking at patients with AF focused on highly selected and symptomatic patients undergoing interventions, with quality of life scales used to assess the impact of the intervention. This was supported by Thrall et al's later review (2006), which found that the majority of studies (89.8%) concentrated on this group. Although these studies tended to demonstrate an improvement in quality of life post intervention, many of them had methodological weaknesses such as small sample size, little or no randomisation and/or a lack of a control group. In addition, many of the studies were carried out on a subset of a larger cohort of clinical trial patients, raising concerns regarding power size.

However, Thrall et al (2006) did identify five studies that looked at quality of life in a "general" population with AF, all of which used the Medical Outcomes Study Short Form-36 (SF-36) to assess quality of life. Four of these studies compared patients with AF with a control group (Dorian et al 2000; Howes et al 2001; van den Berg et al 2001; Kang and Bahler 2004) and three of these reported a poorer quality of life in patients with AF on some or all of the SF-36 subscales, compared with healthy volunteers (Dorian et al 2000; Howes et al 2001; van den Berg et al 2001) and patients with CHD (Dorian et al 2000). One study comparing men and women with AF (Paquette et al 2000) showed that women reported significantly poorer physical and functional heath. However, mental health and well-being scores were virtually identical for men and women.

One of the studies identified by Thrall et al (2006) looked at quality of life in eighty-one patients newly diagnosed with AF within six months. In addition to measuring quality of life using the SF-36 scale, Kang and Bahler (2004) also used the AF symptom frequency and severity checklist. This scale was designed as a disease specific instrument to measure the patient's perception of the frequency and severity of the symptoms of their AF. The study found that quality of life in patients newly diagnosed with AF was significantly impaired and that the subjective seriousness of illness had a pivotal impact on quality of life in AF. The same study was reported on in a later article by one of the authors (Kang 2006), highlighting the fact that there were differences in the types of symptoms reported by younger patients and also that patients with more frequent symptoms perceived poorer physical health and mental health.

In another report of the same study, Kang (2005) also examined the effect of uncertainty of perceived health status in the eighty-one patients. Greater symptom severity was associated with higher uncertainty and those patients with higher uncertainty appraised a greater danger. Greater appraisal of danger was then also associated with the perception of poorer mental and general health. Kang therefore concluded that there is *"a need to reduce perceptions of uncertainty as soon as possible to prevent the negative effects that uncertainty has on mental health"* for this group of patients.

This issue of the psychological impact of AF was picked up by Thrall et al (2007) in their study examining the prevalence and persistence of depression and anxiety in patients with AF. They found that symptoms of anxiety and depression existed in approximately one third of patients with AF, with patients with AF displaying higher levels of anxiety than the control group at baseline. The elevated symptoms of depression and anxiety reported by patients with AF at baseline tended to persist over the first six months of follow up. The authors proposed that these findings suggest that patients with AF experience "significant psychological morbidity" and that this is protracted and not limited to a single observation (p1263).

Thrall et al (2007) also looked at quality of life and its relationship with anxiety and depression in patients with AF. They found that depression and anxiety were strongly associated with quality of life at baseline but at follow up, only changes in

depression were significantly associated with quality of life. From this they suggested that the psychological management of patients with AF should focus on depression as this should translate into improvements in quality of life (p1263).

The psychological impact of AF was expanded further by McCabe (2010) who carried out a review of psychological distress and patients with AF. She conceptualised psychological distress as:

> *"the individual response to a stressor that results in the experience of emotional discomfort and may be manifested by negative affects such as .... depression, anxiety, anger, hostility, and fear." (p41)*

Detailed search terms and inclusion criteria were provided and the author highlighted that only a paucity of studies were found using tested instruments to measure the type and extent of psychological distress and its consequences in patients with AF (McCabe 2010, p40). In total only ten articles were found that met the criteria, with most of these studies looking at the relationship of psychological distress, AF symptoms, and/or health related quality of life. McCabe summarised that the studies showed psychological distress (either depression, anxiety or a combination of both) was present in patients with AF but that the prevalence and severity of this distress was unknown (p48). Reduced quality of life contributed significantly to psychological distress with symptom severity greater in patients with higher levels of psychological distress although the direction of the relationship was not clear. However, McCabe highlighted that it was difficult to summarise the findings of the studies due to diverse study aims and designs (including different methods of sampling and recruitment), the use of different instruments to measure psychological distress and differences in the classification and duration of AF of participants.

The reviews of Jenkins and Bubien (1996), Thrall et al (2006) and McCabe (2010) all emphasised that people with AF experience a reduced quality of life, increased anxiety and/or depression which is reinforced in the findings of Kang and Bahler (2004), Kang (2005), Kang (2006) and Thrall et al (2007).

Building on the theme of psychological wellbeing, Koponen et al (2007) assessed knowledge in 200 patients with AF who visited the emergency room and looked at the impact of knowledge on reported wellbeing. One third of these patients were

presenting with their first AF episode and 26% were presenting with their sixth or more episode. Other than reporting that patients with their first episode of AF were less knowledgeable about anticoagulation than those with a previous AF diagnosis, no distinction is made between knowledge and number of AF episodes. Women had less knowledge than men about AF treatment (including anticoagulation), detection and the impact of AF on everyday life. Patients who reported they felt they were in good general health demonstrated better knowledge about AF symptoms and anticoagulation than those who reported their general health status as poor. Koponen et al (2007) therefore proposed *"knowledge appears to be clearly associated with a patient's sense of well-being and with how they cope with AF".* This agrees with the findings of Kang and Bahler (2004), Kang (2005) and Kang (2006), highlighting the importance of knowledge and understanding of their condition for AF patients. Support, education and information therefore emerge as key themes for patients with AF, both newly diagnosed and with longer lasting histories.

Although a significant amount of the above work has involved interviewing patients with AF , structured survey tools such as the SF-36 have been used as assessment approaches, meaning that the work has been quantitative in approach. Numerous authors have argued that in order to gain an cultural deep insight into the understanding and experience of others, qualitative research is preferred as *"a means for exploring the points of view of our research subjects"* (Miller and Glassner 1997 p100) or for *"eliciting authentic accounts of subjective experience"* (Silverman 2001 p.90). Looking in more detail at the use of qualitative research in a medical environment, Greenhalgh and Hurwitz (1999) say it *"provides meaning, context and perspective for the patient's predicament"* and this is also supported by Charon (2006 p.66) who says *"without the narrative acts of telling and being heard, the patient cannot convey to anyone else … what he or she is going through".*

Despite this and the high levels of AF in the population, there appears to be little qualitative research regarding this patient group. Cinahl, Medline and PubMed searches revealed only a few pieces of qualitative work which are summarised below.

2.4   The patient experience of AF

McCabe et al (2011) interviewed fifteen patients with paroxysmal or persistent AF to explore the experience of living with symptomatic AF as it comes and goes. Patients with permanent AF or silent AF were therefore excluded from their study. Overall the authors identified seven key themes: 1) finding the meaning of symptoms, 2) feeling uninformed and unsupported, 3) turning points, 4) trying to steer clear of AF, 5) managing unpredictable and function limiting symptoms, 6) emotional distress and 7) accommodation tempered with hope for a cure.

Initially participants reported difficulty in identifying the meaning of their symptoms and obtaining a diagnosis with their symptoms often being dismissed by their healthcare professionals. Once diagnosed, some participants felt that healthcare professionals were not informative or supportive and participants reported "inadequate counselling about the nature and trajectory of AF and AF self-management skills" (McCabe et al 2011 p7). Participants experienced emotional distress due to the unpredictability of symptoms and the fact they had no control over when and where an episode would occur and how long it would last. However, participants perceived unsatisfactory emotional support from clinicians, coworkers and family members. The unpredictability of AF episodes meant participants reported anticipatory fear and anxiety about episodes with some developing avoidance behaviours affecting work, exercise, social and recreational activities.

McCabe et al (2011) recommended that psychoeducational interventions similar to those used for other cardiac patients should be developed for patients with AF, addressing emotional distress and counselling patients in self-management skills. The authors also identified that health care providers may not recognise the fear, anxiety and uncertainty experienced by patients with AF and therefore their attitudes about the significance of AF may be an inhibitory factor preventing patients from seeking treatment to manage symptoms and reduce progression of AF. They proposed that more research was required to evaluate the attitudes and knowledge of clinicians to develop "interventions to target areas of knowledge deficit and attitudes that discourage patients from seeking optimal treatment for their AF" (p8).

In summary, the study by McCabe et al (2011) depicted the experiences of patients with PAF or persistent AF as:

"delayed diagnosis, feelings of non-support, inadequate self- management counselling, and distress associated with unpredictable symptoms that require attention of researchers and clinicians" (p8)

Ekblad et al (2012) interviewed twenty five patients with permanent and intermittent/persisting AF to explore and describe critical incidents in which patients with AF experience how AF affects their wellbeing and what actions they take to prevent and handle it. Participants were asked to describe a situation related to AF which influenced their wellbeing, how the situation was handled and to clarify the consequence of the action in the situation. A total of 152 critical incidents were categorised by experience and actions into subcategories which were then divided into categories from which main areas emerged.

Critical incidents influencing wellbeing divided into four categories; bodily impact (such as feeling shortness of breath or an irregular heartbeat); existential impact (such as anxiety, emotional relief when symptoms decelerated); consequences of impact (such as being unsure when symptoms would appear, symptoms being affected by food and drink) and uncertainty about the future (a lack of knowledge about AF and a lack of security in the home environment). Bodily impact and existential impact were combined into the main area of discomfort in daily life and consequences of impact and uncertainty about the future into the main area of limitations in daily life.

The actions that patients took in order to prevent or handle critical situations influencing their wellbeing were divided into six categories in two main areas. The main area of self-care related actions included the categories: patients were in a state of readiness (avoiding symptoms, being prepared for symptoms); patients facilitated or remedied their condition (managed weakness in activity, managed distressing symptoms); patients adapted to the actual condition (managed permanent limitations and managed their social situation) and patients made statements about the need for health care (perceived symptom severity as guiding actions, awaited betterment of symptoms). The main area of healthcare related actions consisted of two categories: patients contacted healthcare personnel immediately if discomfort appeared (visited healthcare faculty immediately or contacted healthcare services by phone immediately) and patients contacted

healthcare personnel when discomfort persisted (contact healthcare services by phone with long-term symptoms or visited healthcare faculty with long-term symptoms).

The authors concluded that AF affected wellbeing when it was uncomfortable and led to limitations in daily life. Patients adapted and developed strategies for self-care based on their experience of AF in order to maintain wellbeing and needed knowledge and practical tools from healthcare providers to help them handle the emotional consequences of AF.

In a study of patients who had highly symptomatic AF and went on to have devices implanted to manage their symptoms Deaton et al (2003) interviewed eleven patients as a sub study of a trial involving assessment of patient acceptance and tolerance of an implantable atrial defibrillation device. These findings provide some useful insight into this subgroup of patients with AF.

The findings are reported in three sections: life pre-implant; decision making & device implantation and life post-implant. Pre-implant themes focused on the process of seeking a diagnosis and a treatment plan, which highlighted misdiagnosis, minimisation and poor treatment and how patients endured distressful treatment in the pursuit of success in managing their condition. Patients reported doctors saying to them "*You just have to learn to live with it*" and *"there's nothing you can do for AF"*. Decision making and device implantation reflected the impact of AF in these highly symptomatic patients who felt they had *"no more choices"* and had come to *"the end of the road".* One interviewee demonstrates this eloquently:

> *"I couldn't do anything. Just no quality to my life. I was a hardship to my family. I felt like if there was a chance I could get back into the mainstream of civilization, I surely wanted to do it. I was willing to take substantial risks to do that."* (Deaton et al 2003, p.296)

Post-implant, overall perceptions were that the device had led to an increased quality of life, despite the associated shock experiences. Patients were asked to provide suggestions regarding preparation and support for similar patients in the future. Comments included that patients be encouraged to obtain support from significant others such as spouses and families and that a support group would be beneficial.

Patients acknowledged the positive support provided by the clinical research team in this study and emphasised that greater support would be needed over time to support adaptation to the device. The authors concluded with concepts for inclusion in protocols for prospective users of this device, which included education of patients and their families and the facilitation of social support.

The small amount of available qualitative research providing an insight into the experience of living with AF clearly demonstrates that AF has a significant impact on the psychological wellbeing of patients, with themes of support and information from healthcare professionals emerging as important for this patient group. The impact of AF on psychological wellbeing is reinforced by the quantitative studies that highlight the impact of AF on quality of life, anxiety and depression.

2.5   AF and Policy

Considering the impact on healthcare systems, AF is consistently in the top ten reasons for hospital admission and absorbs almost 1% of the entire budget of the NHS. It therefore has a significant impact on the provision of healthcare services in the UK (Stewart et al. 2004) and recognition of its impact has led to an increased importance in the context of healthcare practice and policy (Banner 2008).

National Service Frameworks (NSFs) arose from New Labour policy as a method of bringing "*together the best evidence of clinical and cost-effectiveness, with the views of service users, to determine the best ways of providing particular services*" (Department of Health 1998, sec. Setting Quality Standards) and in 2000, the Government launched the Coronary Heart Disease (CHD) NSF (Department of Health, 2000), which focused on dealing with prevention and treatment of coronary artery disease, giving clear targets and standards. Reviewing progress in 2005, John Reid, the then Secretary of State for Health, said that the first seven chapters of the CHD NSF had led to "impressive improvements" in tackling coronary heart disease (DH Coronary Heart Disease Policy Team, 2005, p. 1). However, arrhythmias were not covered by these first seven chapters of the CHD NSF.

The Department of Health then launched an additional chapter of the CHD NSF-Chapter Eight, (Department of Health 2005a) which focuses on arrhythmias and sudden cardiac death. The chapter laid out three quality requirements and twenty

markers of good practice that would "*enable the NHS to deliver the highest quality of care to people whose lives are affected by arrhythmias*" (Department of Health 2005a, p. 1). Quality requirement one focused on patient support aiming to improve the practical and emotional support offered to people with arrhythmias and their families by ensuring "*people with arrhythmias receive timely and high quality support and information, based on an assessment of their needs*" (Department of Health 2005, p. 7). Markers of good practice stated that people with arrhythmias "*receive a formal assessment of their support needs*" and that those with long term conditions "*receive support in managing their illness from a named arrhythmia care co-ordinator*" *(*Department of Health, 2005, p. 8)

Following the publication of Chapter Eight of the CHD NSF, the British Heart Foundation (BHF) funded a programme of arrhythmia care coordinator (ACC) posts across England and Wales. The funding supported 32 new ACC posts and all appointees were registered nurses with the majority being given the title of Arrhythmia Nurse Specialist (ANS) (Ismail and Lewin, 2010). The evaluation of this funding (Ismail and Lewin, 2010) and an associated journal article (Ismail and Lewin, 2012) provide some insight into the support provided for patients with AF, although the arrhythmia care coordinator posts were not solely focused on patients with AF but included a range of patients with arrhythmias presenting to a specialist arrhythmia nurse.

Ismail and Lewin (2012, p.177) describe the role of the ACC to "*improve the educational, emotional, and practical support offered to patients and their families*". The interviews with patients and carers that formed part of the overall evaluation of the BHF funding demonstrated that the specialist nurses "*took the needs of patients and caregivers into consideration and acted as a major form of support, providing much needed information, taking time to hear their concerns, and providing explanations and reassurance*"(Lewin and Ismail, 2012, p.180). In addition to providing this support, patients also described that the ACCs had delivered personalised coordinated care and had improved accessibility of clinical advice to address issues or concerns. They had also provided practical help such as relaxation tapes and psychological support, helping them to come to terms with their condition.

Although the evaluation of the BHF ACC posts provides some indication of the support that these roles provide to patients with arrhythmias, there is little literature available to identify the specific support needs of patients with AF. This study therefore aims to look in more depth at the issue of support provided by healthcare professionals for patients with AF.

3   Support from Healthcare Professionals - A Review of the Literature

AF is now recognised as "life-complicating chronic illness" (McCabe, 2010, p.40) and therefore can be considered as a long term condition (LTC). LTCs have been described as "*those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies*" (Colin-Thome, 2007). Support for such patients and their families features strongly in recent strategy and policy documents such as the National Stroke Strategy (Department of Health 2007a) and the National Cancer Survivorship Initiative (Department of Health et al 2010) and is inherent in self- care and self- management of long term conditions (Department of Health 2006). Therefore the literature review for this study examined key issues of support by healthcare professionals for people with long term conditions to inform the concept of professional support for people with AF. This chapter will provide an overview of the search strategies undertaken to review the literature and will then critically discuss relevant evidence.

3.1   Literature searching

The search strategy for this dissertation utilised a range of methods over the seven year period of part time study for the professional doctorate. As a result, material was searched and critiqued over a period of years with new evidence included as the study progressed.

Although frequently mentioned in policy documents as detailed above, there is little clarity in the understanding of what support from professionals actually constitutes. Support itself is a multifaceted word, with twenty meanings in one dictionary (Collins 2005, p.1618), including "*to give aid or courage to*" and searching the published literature reveals wide variation in the use of the term "support". Therefore in an attempt to get a clearer understanding of this support a literature review was carried out with the aim of defining "professional support" in the context of a patient with a long term condition such as AF.

Initial exploratory searches using the keywords "professional support" were carried out in PubMed, Cinahl and PsychInfo which resulted in an unwieldy number of

articles (over 4,000 in PubMed alone) with the main emphasis appearing to be on support of professionals (such as professional development and peer support in different professional groups) as opposed to support provided by health professionals to patients with long term conditions.

Using the commonly used building block style of searching (Booth, 2008) and adding "atrial fibrillation" to the professional support search using the Boolean AND operator returned a limited number of articles (decreasing from over 4,000 to 29 in PubMed) none of which were relevant to the concept of professional support being considered for this study, focusing mainly on decision making regarding anticoagulation for people with AF. Replacing atrial fibrillation with the keywords "long term conditions" narrowed the number of articles significantly (to just over 100 in PubMed from the previous over 4,000) but again few of these articles had little relevance to the concept of professional support being considered for this study.

Background reading to develop the research proposal for this study had also led to the field of social support to inform initial thinking. This reading highlighted the difficulties in searching for relevant evidence when there was a large body of evidence using the same term with different meanings. For example, searching PubMed using the keywords "social support" resulted in over 16,000 articles being identified. Given the large amount of literature on social support and the difficulty in locating relevant literature regarding professional support, initial background reading focused on books and review articles in the social support field in order to try and identify key authors and pieces of work that might inform the work regarding professional support.

Booth (2008, p.315) highlighted "berry picking" as an appropriate model of information retrieval to help refine searching. This involves starting with a wider query and using the findings to help narrow in on authors or treatments that are relevant. Booth highlighted that whilst this is not an appropriate method for a rigorous systematic review, it is useful for initial scoping and defining concepts. From here, additional tactics such as citation searching and author searching are used to locate literature relevant to the subject being reviewed.

Through the adoption of a berry picking approach as defined by Booth (2008), a review article in the field of social support by Williams et al (2004) was detected. The

authors were attempting to identify definitions of social support and they described how there has been "*a proliferation of definitions and theoretical discussions of the concept of social support*" (Williams et al, 2004, p. 943). It is relevant to note that the authors experienced search difficulties when attempting to identify definitions of social support when initial searches yielded what they describe as "*an unwieldy number of articles*" (Williams et al, 2004, p.946). They chose to add terms such as "*definition, concept, theory, meaning and instrument*" to "social support", which resulted in more manageable results. From these results they then carried out a snowball technique to identify relevant articles from reference lists which they felt confident represented the bulk of available evidence.

The Williams et al review (2004) highlighted above revealed Judith Hupcey as a key author. As suggested by Booth (2008), author searching for her work identified an article specifically addressing the issue of social support provided by professionals. Using the Web of Science, this article was then used to both forward and backward chain for other relevant articles (Booth 2008). Creswell (2009) advised researchers using computerised databases to undertaking literature reviews that by finding an article close to the topic of interest, the search terms from that article could then be used to define the search terms for the databases. This approach was then applied to searching together with the snowballing approach adopted by Williams et al (2004) and the berry picking strategies described by Booth (2008) detailed earlier to identify relevant literature in the professional support field.

Booth (2008) described such an approach to literature searching as "supplementary" to the "*rigorous and systematic approach*" undertaken using building block techniques (p.316). However, it is important to acknowledge that in this study as the traditional building block technique did not provide any relevant and current material (University of Ulster, 2010), it was necessary to adopt other approaches to facilitate effective literature searching for this study and to ensure that all applicable literature was identified.

As previously mentioned, searching of the literature took place over the period of doctoral study. With the challenges described in identifying evidence using the building block technique, a continuous process of snowballing, forward and backward chaining of key articles and the use of search terms from identified articles

to repeat searches was adopted throughout the study to ensure the discovery of all relevant articles. Investigation of areas of similarity to professional support (such as social support, supportive care and self-care management) was also undertaken to detect any additional relevant information and these areas are outlined in the literature review to describe how they link with the area of interest.

3.1.1 Inclusion and exclusion criteria

The berry picking process identified a variety of studies exploring support for patients with long term conditions as well as with other more acute conditions. There was a range of studies looking at the support provided through relationships of friends and family, some studies that focused on the types of support provided by friends and family but a paucity of studies focusing solely on the types of support provided by healthcare professionals for patients with long term conditions. In order to address the research question, studies were included in the literature review if one element focused on the types of support provided by healthcare professionals. Main attention was paid to those studies that looked at populations with a long term condition, but given the small amount of relevant evidence, studies considering more acute conditions were also included. Only studies with adult populations were included. Only papers in the English Language were considered and no date limits were set. Qualitative, quantitative and mixed methods studies were included.

Studies focusing on professional support defined as peer support for healthcare professionals were excluded as were studies that focused solely on relationships as support. Studies that only considered the types of support provided by friends and family were also excluded as they did not address the specific focus of this study - support provided by healthcare professionals.

3.1.2 Critical appraisal

Studies were assessed for quality using the approach outlined in the Critical Appraisal Skills Programme checklists[3] to determine whether the results were valid, what were the results and were they of use to this study. Given the paucity of evidence identified, studies were not excluded on the basis of quality but issues that may affect the weight of evidence that were identified through the critical appraisal process were noted and are highlighted in the literature review,

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[3] For more information of the Critical Appraisal Skills Programme and checklists used, see http://www.casp-uk.net/

3.1.3 Summary – literature searching

Having adopted a multifaceted approach to searching as outlined above throughout the course of doctoral study, the searches that were carried out were felt to be wide-ranging and encompassing the bulk of the relevant literature in the field despite the noted challenges.. The reviewed literature is described in detail below together with an overview of areas of similarity to professional support that informed the development of the research question. Theoretical and empirical evidence is critically appraised in order to establish a working concept of professional support.

3.2   Social support

One of the main themes in the social support literature looks at the impact of social support on health outcomes and demonstrates the importance of adequate social support for positive health outcomes in a range of conditions including coronary heart disease, stroke, anxiety and depression. (For examples see Schaefer et al, 1981; Uchino et al, 1996; Lett et al, 2005 and Ikeda et al 2008 amongst others.)

Despite a significant body of work looking at social support, House et al (1988) highlighted that there is not a clear definition of the term; instead related terms were used interchangeably generally focusing on the consequences of social relationships for individual health and wellbeing. Schaefer et al (1981) suggested that this is due to a basic confusion about the nature of social support. Social networks, social integration, perceived social support and social relationships were all phrases identified as being used to investigate social support (Schaefer et al, 1981; House et al, 1988) with the consequence of limiting the extent to which research findings can be generalised and integrated.

Hupcey and Morse (1997) reiterate this issue by highlighting that "*almost anything tangentially related to support has been considered social support*" (p.270). They suggest that this is due to a lack of clarity of the term social support, which has allowed researchers to use it in relation to any "*potentially positive relationship irrespective of provider*" (Hupcey and Morse, 1997, p.270). This builds on the debate in the social support literature as to whether there are links between social support provided through informal networks (family/friends etc.) and that of professionals.

Stewart (1993) proposes that there are "clear commonalities and distinctions" between nursing support and social support:

> "Nursing support is a formal, professional source of support. Social support, although generally derived from informal, lay sources, occasionally and temporarily can be obtained from formal sources." (p. 64)

On a similar vein, Fingfgeld-Connett (2007) considers the concept of caring with her qualitative concept comparison between caring and social support and concludes that caring and social support are *"different processes that predominately exist in separate domains"*, (p.58) with caring being located in the professional paradigm of nursing whilst social support sits with lay providers. This would appear to be at odds with Stewart's view of social support being provided on a temporary basis by professionals (1993). However, Finfgeld-Connett does go on to acknowledge the evidence supporting the provision of social support by healthcare professionals when other factors (such as time, geographical distance, stigma) prevent it being delivered by lay providers.

This develops Stewart's (1989) earlier proposal which suggests that professional support should be thought of as: *"surrogate support that extends or replaces support that is not available in the client's network"* (1989). This has also been proposed by Norbeck (1998) who suggests surrogate support for individuals with inadequate support networks "*might be temporary, as during a crisis".*

Rook and Doley (1985) take a more cautious note to this concept of surrogate support and highlight the fact that:

> "Social support achieved through interventions should not be assumed to be equivalent in its form or effects to social support normally available from one's family and friends" (p.10)

Nonetheless, they temper this with the fact that *"this is not a serious concern" (*Rook and Doley 1985, p.10) if existing support networks are inadequate.

It appears that there is some consensus in the field that although social support is traditionally provided through informal relationships, there may be a role for

healthcare professionals to deliver surrogate social support at certain times of crisis or inadequacy. However, the emphasis of this work on surrogate support from healthcare professionals appears to be on the social networks, integration and relationships explanations of social support.

3.3 Professional Support

Hupcey and Morse (1997) however dispute the notion that professionals provide social support, acknowledging that whilst professionals may provide support to an individual this should not be considered as social support. Instead they describe professional support as "*support that professionals provide by virtue of their role*" (Hupcey and Morse 1997, p.273) and suggest that the differences between social support and professional support are due to the nature of the relationship between the provider and recipient of support, with the relationship between a professional and patient being based on certain role expectations (Hupcey and Morse 1997, p. 275). These differences are outlined below in Table 1.

Table 1: Comparison of the major characteristics of social support and professional support

Characteristics	Social Support	Professional Support
Types of services provided	Open	Delimited
Duration	Must be developed	Instantly available
Trust	Reciprocal (shared)	Unilateral
Obligation	Kinship/friendship	Professionally defined or surrogate
Expectations of relationship	Based on congruent expectations	Based on role expectations
Reciprocal action	Equivalent	Not required, services "purchased" or financially compensated

(Hupcey and Morse 1997, p.273)

With the exception of the characteristic "types of services provided", Hupcey and Morse's model reinforces the focus on the relationships component of support, highlighting the differences concerning relationships between patients and healthcare providers. However, considering the body of work that proposes that

support from professionals may act as a surrogate for social support, these relationship factors may not be significant and therefore it is important to consider the **type** of support provided.

3.4 Types of support

More recently there has been a move to separate social support into structural versus functional social support emphasising the "*distinction between existence of social relationships and the functions provided by these*" (University of Wales Institute 2014). Schaefer et al (1981) introduced the concept of types or functions of social support and the importance of distinguishing between them as "*they may have independent effects on health and psychological functioning*" (Schaefer et al 1981, p386). They proposed three separate types of social support: emotional, tangible and informational which are shown in Table 2.

Table 2: Types/Functions of Social Support

Types/Functions of Social Support	Components/Elements of Support
Informational	- Giving information and advice which could help a person solve a problem - Providing feedback about how a person is doing
Tangible	- Direct aid or services (including loans, gifts of money or goods) - Provision of services (including taking care of needy persons or doing a chore for them)
Emotional	- Intimacy and attachment, reassurance, and being able to confide in and rely on one another - All of which contribute to the feeling that one is loved or cared about or even that one is a member of a group, not a stranger

Adapted from Schaefer et al (1981)

Occasionally researchers have proposed esteem/affirmational support as a fourth type of social support, describing it as a particular form of social support that is provided with the intent of enhancing how others feel about themselves and their attributes, abilities, and accomplishments (Holmstrom 2012). However, the most established models of social support feature the three types of social support described above with esteem/affirmational support incorporated as part of emotional support (Costello 2012). Therefore this tridimensional model of the types of social

support will be used to consider whether it also provides an appropriate framework for the types of professional support.

3.5   Types of Professional Support

Although the structural elements of social support and professional support may differ in characteristics as described above, there are clear parallels between the three types of social support proposed by Schaefer et al (1981) and the types of support provided by healthcare professionals. Miles et al (1999) developed the Nurse Parent Support Tool (NPST) using a model of nursing support based on Schaefer et al's (1981) three types of social support and proposed that the concepts used to define social support had relevance to professional intervention as they included many areas of interpersonal support provided by nurses to patients and their families, which they conceptualised as "professional support" (Miles et al 1999, p.46). Miles et al (1999) clearly defined the framework of social support used to develop their tool and provided detail on how they used existing literature, qualitative interviews with parents and sense checking from clinicians to identify key items that reflected supportive behaviour from nurses. They also described how individual items were mapped to different types of professional support, clearly demonstrating how the NPST was developed from the theoretical framework of social support.

Koivula et al (2002) also used the three dimensional model of social support to develop the Social Support from Nurses (SSN) scale to measure the amount of in-hospital social support from nurses for patients undergoing coronary artery bypass graft (CABG) for cardiac disease. They reported mapping the professional actions of nurses into each of the three types of social support. For example, emotional support related to asking about feelings, listening to the patient and showing the patient respect; informational support related to illness and health related information and patient education as well as information to carers and family members and tangible aid was defined as practical nursing procedures performed by the nurse if the patient couldn't cope. However, no detail was provided as to how these professional actions were identified as the most relevant/appropriate for inclusion to measure in-hospital social support from nurses. The authors did report that there was no suitable measure for measuring social support (hence the development of the SSN) and their

work does reinforce the approach of using social support to measure support provided by healthcare professionals.

Dakof and Taylor (1990), Martin et al (1994), Warwick et al (2004) and Masters et al (2007) investigated the specificity of social support by provider and extended the support providers to include healthcare professionals. Dakof and Taylor (1990) and Warwick et al (2004) included physicians and nurses, physicians were the only professionals considered in the work of Martin et al (1994) and Masters et al (2007) included physicians and physical therapists in their study of patients with low back pain. Dakof and Taylor (1990) developed their original questions to build on previous work exploring victimising events and the need for social support but their work focused on the type of support from different providers. There is a clear description of how items were coded as different types of support, providing a robust description of data analysis.

Martin et al (1994), Warwick et al (2004) and Masters et al (2007) used the same question as Dakof and Taylor (1999) to ask participants to describe the most helpful and most unhelpful thing that each provider had said or done and used the tri-dimensional model of types of support (emotional, informational and tangible) to code responses to develop an understanding of the component parts of each type of support.

These examples show practical incidences of applying the three types of social support to investigate the support provided by healthcare professionals, demonstrating this to be a valid method to explore this topic in more detail. The existing evidence regarding these three types of support provided by healthcare professionals will be now explored separately.

3.5.1 Tangible support

Hupcey and Morse (1997) also used the same types of social support to highlight the differences between social support and professional support. However, their theoretical paper suggested that professionals only provide certain services to their patients and that these were usually specified by policy or standards of practice. Additionally, although professionals may provide emotional and informational support, tangible aid was not usually provided. However, although their paper provided descriptions of some evidence to support their theory, there was no

information regarding the processes they adopted in selecting the evidence for discussion. Therefore, relevant articles may not have been included so it is not clear how they arrived at their view that tangible aid was not usually provided by professionals.

Miles et al (1999) discussed the issue of tangible support in describing the development of their instrument to assess perceptions of nursing support. They originally assumed that tangible support would relate to practical assistance such as making coffee for parents but having carried out interviews to develop their model, it became clear that participants viewed tangible support as quality of care. The development of their model has a robust approach including checks for content validity with clinical experts and parents, providing confidence in the findings. This has a fit with the approach of other authors investigating the types of helpful and unhelpful support they have received and contrasts with the view of Hupcey and Morse (1997) that tangible aid is not provided by professionals.

In their study of 193 patients undergoing CABG, Koivula et al (2002) reported that nearly all the patients in their study had received "*much or very much tangible aid*" (p.420) using a five-point scale from 1 (not at all) to 5 (very much). Patients were asked to assess the social support received from nurses on the pre-operative day and three examples of tangible support were included in their questionnaire: hospital gives advice on how to act in the hospital environment; nurse helps in all matters if patient is unable to cope and nurses are quick to help when needed. Only 2-3% patients reported receiving no/low tangible support from nurses across all three categories. Interestingly, the examples of tangible aid used in the SSN all related to the practical assistance that Miles et al (1999) initially assumed would constitute tangible aid. There was no inclusion of items relating to nursing competency which could have been expected based on the findings of other authors who have proposed medical care as tangible aid (Dakof and Taylor, 1990; Martin et al, 1994; Miles et al 1999; Warwick et al, 2004 and Masters et al, 2007). It is worth reiterating that Miles et al (1999) reviewed their instrument in light of findings from interviews at the development phase and as stated earlier, it is not clear how the items for inclusion in the SSN were generated, raising questions as to the accuracy and completeness of Koivula et al's definitions of tangible support.

Exploring other social support work that includes tangible support provided by healthcare professionals, Dakof and Taylor (1990) asked 55 patients with cancer to describe the most helpful and least helpful thing that different groups of people (including friends, family, physicians and nurses) had said or done. Examination of responses showed that regarding physicians, 27% of respondents gave answers relating to technically competent medical care, which the authors coded as helpful tangible aid and from nurses, 18% of respondents reporting practical assistance which was coded as tangible aid. 14% of respondents also highlighted incompetent medical care from physicians as the least helpful support which was coded as unhelpful tangible aid. Dakof and Taylor clearly outlined their coding processes which allows consistency and cross-checking with authors who adopted their approach in future studies and providing reassurance of the accuracy of their definitions of tangible support

Masters et al (2007) repeated the questions of Dakof and Taylor (1990) with 50 patients with low back pain and found when asked about the support provided by physicians, the most common support type given was tangible support. Martin et al (1994) who investigated support in 53 people with irritable bowel syndrome (IBS) or recurrent headache also found that respondents identified tangible aid from professionals. However, with regard to unhelpful support, where respondents described the most unhelpful type of support they had received, Martin et al (1994) specifically attributed this to incompetent medical care. As in the Dakof and Taylor (1990) study, both Masters et al (2007) and Martin et al (1994) detailed their coding processes, providing reassurance of their definitions of tangible support.

Warwick et al (2004) carried out eight in depth interviews with women with chronic pelvic pain (CPP) who were identified as part of a companion study. The interview participants were the first eight people to reply to the invitation to participate raising concern as to whether data saturation was achieved in the sample. However, Warwick et al (2004) clearly describe their theoretical framework of social support, state their methodology and describe how they code the findings into types of support that had been helpful and unhelpful from different support providers including doctors and nurses, using the questions developed by Dakof and Taylor (1990). Competent medical skills were reported as the most useful type of tangible support from both doctors and nurses. However, incompetence and unsatisfactory

treatment were also reported as unhelpful tangible aid and the authors particularly highlighted the fact that doctors were "*at a loss*" regarding a solution to CPP as a specifically unhelpful tangible support (Warwick et al 2004, p.123). Although there are some potential issues with sampling in this study, the findings regarding tangible support as competent medical skills support the findings of other work in this field.

Therefore, despite the views of Hupcey and Morse (1997) that tangible support is not a type of professional support, there is a body of work clearly defining types of tangible support that are indeed provided by healthcare professionals, in the form of provision of medical care and other practical assistance.

3.5.2 Informational support

The need for informational support from healthcare professionals has been considered by a variety of authors across a range of different conditions (Sanson-Fisher et al 2000; Bonevski et al 2000; Moses et al 2007 and Davidson et al 2008). Looking specifically at cardiac conditions, information needs have been positioned as the highest priority in most studies of patients and their families (Moser et al 1993). Scott and Thompson's (2003) systematic review identified fourteen studies investigating the information needs of patients post myocardial infarction (MI). The review had clear inclusion and exclusion criteria, provided detail of the search strategy and provided an overview of studies that met the inclusion criteria but could not be used in the meta-analysis as they used a variety of instruments that meant the results couldn't be combined, giving assurance in the completeness of reporting and the robustness of the findings of the review.

The review found that information about risk factors was ranked as the most important category overall, followed by information on cardiac anatomy and physiology, medications, and physical activity. The review discovered differences in needs between those identified by patients and those that nurses thought patients needed. It also highlighted that patients preferred doctors over nurses as providers of information. The authors did identify that whilst the studies provided detail on informational support for this group of patients, there had been no involvement of patients in the design of questionnaires used to assess information needs and therefore key aspects of informational need may not have been considered.

Koivula et al's (2002) SSN scale included four elements of informational support for patients undergoing CABG and reported that the majority of the 193 patients received "*much informational support from nurses*" (p.420) with the majority reporting that the informational support was exactly what they needed and helped them understand their care. They did identify a deficit of informational support with a third of patients reported that their family had received little or no information. As highlighted earlier, it is not clear how the items for inclusion in the SSN scale were generated and it may be that key aspects of informational support from the perspective of the patient were not incorporated as with the studies examined in Scott and Thompson's (2003) review, leading to a potential gap in understanding of informational support requirements.

Boutin-Foster's (2005) qualitative study of 59 patients who had been hospitalized for an acute coronary syndrome used a framework of social support but did not provide detail on the components of the different types of support. However, the analysis did identify the provision of informational support by healthcare providers as problematic. Participants reported that healthcare providers told them too much with one specifically saying "*Don't tell me things that are going to worry me"* (Boutin-Foster 2005, p.55). Information was often considered to be incomplete with participants reporting being given advice to change health behaviours but not the support to make these required changes which was described by the authors as "*information without practical means for implementation*" (Boutin-Foster 2005, pp.55-6).

Dakof and Taylor (1990) reported that 38% of patients with cancer in their study identified the provision of medical information (i.e., informational support) as the most helpful support from physicians. Conversely, 25% reported giving insufficient medical information as the most unhelpful thing their physician did, showing the importance of informational support from healthcare providers for patients with cancer. The types of informational support were clearly described, allowing comparison with similar work that followed, including that of Masters et al (2007) and Warwick el al (2004) both of which looked at informational support from professionals.

Masters et al's (2007) study of patients with low back pain identified that the most common report of unhelpful support from physicians was informational support (28%

of respondents) and Warwick et al (2004) also reported similar accounts of unhelpful informational support in their study with women with chronic pelvic pain. It is possible that these two descriptions of unhelpful informational support may be explained by the authors who described that this unhelpful support tended to be reported when patients found the doctor's explanation of their pain "*unsettling*" (Warwick et al 2004, p.17) including examples such as "*he thinks the pain is all in my head*" (Warwick et al 2004, p.17).

The evidence suggests that information is a key element of the support that patients wish to receive from their healthcare professionals but that this informational support is often not matched to their needs/wants. Although the evidence from some studies has been developed directly from the needs expressed by patients, it is not clear whether informational support identified in other studies actually covers all informational support needs of patients. Therefore there is a need for further work to confirm specific components of informational support provided by healthcare professionals.

3.5.3 Emotional support

Looking at patients following an acute cardiac event (MI or coronary artery revascularisation), Moser et al (1993, p.107) reported that the "*needs for reassurance and relief from anxiety, and the need for hope have been consistently identified as extremely important*" for patients and their spouses. Moser et al also highlighted that appear to be differences though between different professional groups as to how well they provide their patients with such support with nurses identified as a key group to deliver such support.

Koivula et al (2002) reported that participants in their study of 193 patients with CABG felt they received plenty of emotional support from the nurses. They also identified that there appeared to be an association between emotional support from nurses and fear and anxiety; those patients who reported having received less emotional support tended to report higher levels of fear and anxiety before their operation, highlighting the importance of emotional support before a cardiac procedure. As with informational and tangible support in their study, no detail was provided as to how the components that were studied were identified, raising

concern that some relevant components of emotional support may not have been included.

In evaluating the impact of BHF funding for arrhythmia nurse specialists, Ismail and Lewin (2012) interviewed patients with an arrhythmia and their family/carers treated by these nurses. They found that the specialist nurses acted as a major form of support, "*taking time to hear their concerns, and providing explanations and reassurance*" (Ismail and Lewin 2012, p.180), i.e.) clearly delivering emotional support. Whilst these three studies all highlighted the issue of emotional support, no definitions of emotional support were provided, making it hard to identify components of emotional support provided by professionals. However, it is clear from the broader descriptions in the study that healthcare professionals did indeed provide emotional support.

Considering in more detail the role of nurse specialists in delivering emotional support, Wilson et al (2006) investigated the relationship between nurses and patients with chronic illness. Their study described sampling, theoretical frameworks, methodology including data analysis and examined both patients and health professionals, giving confidence in their findings. They reported that patients felt that meeting their emotional needs was a clear area of nursing expertise. However, non-specialist nurses did not describe meeting the emotional needs of patients as one of their key skills, taking a more biomedical approach to their relationships with patients and describing patients who focused on the emotional consequences as difficult. On the other hand, nurse specialists did articulate themselves as having the skill of meeting the emotional needs of patients with chronic illness. There appears to be variability in the skills and experience of nurses which may influence their ability to provide emotional support to patients and this suggests that nurse specialists in the field of arrhythmias appear to be best placed to deliver emotional support for patients with AF.

Looking at emotional support in other conditions, Slevin et al (1996, p.1277) studied 431 patients with cancer using their own definition of emotional support (with little information provided as to how that definition had been developed). They found that "*Patients rated emotional support from senior doctors at least as highly as that from their family, and more important than any other source*". Ward sisters were seen as

more important for the provision of emotional support than junior nurses. However, Arora et al's (2007, p.479) secondary analysis of data collected for a large randomised controlled trial of patients newly diagnosed with breast cancer found "*only a minority considered (healthcare) providers to be a source of helpful emotional support*". They reported that "*cancer patients' concerns and feelings are given relatively limited attention by health care providers*" (Arora et al 2007, p.483) and proposed that providers needed education to enhance their skills to provide emotional support to patients. In line with the other studies described earlier, Arora et al (2007) did not provide detail of how components of emotional support were identified in their study.

Palsson and Norberg (1995) implemented changes in nursing care with an emphasis on emotional support for patients with breast cancer in a small study of 26 women with no control group. Their findings showed that this intervention led to feelings of safety and security as well as indicating an improvement in sense of control. Krishnaysamy (1996) interviewed eight patients with a haematological malignancy to find out their views as to supportive and unsupportive behaviour of nurses and found that emotionally supportive behaviour patterns were considered most useful of interactions with nurses. Conversely, the most unsupportive nurse behaviours were those that patients perceived to be devoid of an emotional component. Although these are small studies, they did detail the components of emotional support provided and therefore suggest that nurses have the potential to provide emotional support for their patients, especially in cancer.

However, the picture regarding provision of emotional support by other healthcare professionals is mixed. Dakof and Taylor also (1990) found that patients with cancer reported modest incidences of helpful emotional support from physicians with 40% of the 55 patients complaining about not receiving enough emotional support from their physicians. This evidence suggests that patients with cancer would like to receive emotional support from their doctors but that this was often lacking.

It is, however, important to acknowledge that the support needs of patients with cancer may differ to those of patients with more chronic conditions such as AF due to the way cancer is socially construed. Martin et al (1994) categorised cancer as a "*catastrophic life-threatening disorder*" and predicted that emotional support may be

higher for this group than for other non-life-threatening non-catastrophic conditions such as IBS and recurrent headaches. They repeated the methodology used by Dakof and Taylor (1990) with 53 patients suffering from IBS or recurrent headaches and compared both sets of findings. Martin et al (1994) found that there was indeed more emphasis on tangible assistance and less on emotional support for patients with these two chronic conditions than their counterparts in the cancer study, suggesting that emotional support is perceived as more valuable in patients with a life-threatening condition such as cancer.

Masters et al (2007) used the same methodology to investigate preferences for support in patients with low back pain and predicted that patients with low back pain were more similar to the patients with headaches and irritable bowel studied by Martin et al (1994) than to the patients with cancer studied by Dakof and Taylor (1990) and therefore tangible support would be seen as more helpful than emotional support. Tangible support was indeed more frequently identified as most helpful especially from physicians than emotional support. The work of Dakof and Taylor (1990), Martin et al (1994) and Masters et al (2007) suggests that those people with a condition perceived to be more catastrophic would require more emotional support from their healthcare professionals.

Masters et al (2007) also included physical therapists in the providers of support that they investigated. The interactions with physical therapists were seen as supportive across many dimensions with only four instances of unhelpful support identified as being provided by physical therapists. The authors described how "*physical therapist optimism based on a real understanding of the problem*" (Masters et al 2007, p.18) was reported repeatedly and suggested that this combination of emotional and tangible support may be provided in ways that are "*similar to how psychologists and other mental health providers are trained to interact with patients*" (Masters et al 2007, p.18). Acknowledging that these findings may not be generalizable to other therapy settings, the authors go on to describe how the physical therapist may be "*uniquely suited in terms of knowledge, time, and resources to provide these essential forms of support*" (Masters et al 2007, p.18).

3.5.4 Summary of types of professional support

From the evidence reviewed, the use of the three dimensional model of social support to describe the types of support that patients would like to receive from their healthcare professionals appears to be a valid approach. The evidence suggests that patients do require emotional, informational and tangible support from their healthcare professionals but this support is not always forthcoming. People with a more chronic/less catastrophic condition appear to find tangible support more useful than emotional support from their healthcare professionals.

There are however issues of quality with the existing evidence. Some studies had small sample sizes and/or provided little detail regarding how participants were recruited raising issues of generalisability. Other studies looking specifically at types of support provided by healthcare professionals have limitations due to the fact that they have not described how these items were identified for inclusion as components of support and therefore it is not clear as to whether all relevant components of support have been included. It is important therefore to gain a clearer understanding of the components of each type of support for patients with long term conditions to ensure that healthcare professionals are able to meet the needs of their patients. Although the literature provides an indication of professional support needs for patients with long term conditions, there is no specific information regarding patients with AF.

3.6   Framework for professional support

Having reviewed the available literature, professional support in this study is conceptualised as the content of the interpersonal interaction with a healthcare professional that the person with a long term condition perceives as helpful or unhelpful, based on Schaefer et al's (1981) conceptualisation of social support.

A framework for professional support has been developed using the three main types of social support and the work of other authors looking at support from professionals. This framework is shown in Table 3 below.

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Table 3: Framework of Professional Support

Types/Function of Professional Support	Components/Elements considered helpful support	Components/Elements considered unhelpful support
Informational	- Providing useful information or advice - Optimistic about prognosis - Acting as a positive role model - Giving information and advice which could help a person solve a problem - Providing feedback about how a person is doing	- Criticism of patient's response to condition - Minimised impact of condition on patient - Acted as poor role model - Provided insufficient information or bad advice
Tangible	- Provision of effective practical assistance - Provision of technically competent medical care	- Provided technically incompetent medical care - Provided unwanted practical assistance
Emotional	- Physical presence - Expressed concern, empathy or affection - Calm acceptance of condition - Was pleasant and kind	- Expressed too much worry or pessimism - Expressed little concern, empathy or affection - Avoided social contact with patient - Rude or inappropriate behaviour

Given the limited literature focusing on professional support, other similar areas of literature were also examined to see if they could add to the proposed framework, given their close links to the concept of professional support. These areas include supportive care and self-care management and these will now be discussed.

3.7 Supportive Care

The concept of supportive care has developed from work in the field of oncology and it is interesting to note that there is a lack of clarity around the term "supportive care" with few definitions of the term exist (Richardson 2004), which demonstrates close

parallels with the concept of social support as mentioned earlier. However, NICE (2004, p.18) has proposed a definition for supportive care for patients with cancer:

> *"Supportive care is that which helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment."*

Despite this definition, there seems to be ambiguity surrounding the definition and contents of supportive care. Searching the Cochrane database of systematic reviews shows there to be variation in how authors undertaking reviews of supportive care define the topic: Cruickshank et al (2008, p.3) stated that supportive care "*is frequently interpreted as a vague umbrella term*", the Non-Small Cell Lung Cancer Collaborative Group (2008, p.2) suggested a more medicalised approach saying that it may include "*palliative radiotherapy, antibiotics, corticosteroids, analgesics, antiemetics, transfusions and psychosocial support*". Ahmed et al (2004, p.2) described supportive care as "usually not well defined" and "left open to local interpretation" and all reviewers highlighted the fact that this lack of clarity makes it difficult to evaluate the impact of supportive care.

Of particular interest with regard to AF is the fact that the supportive care literature has started to broaden beyond the field of oncology. Ahmedzai and Walsh (2008, preface) proposed that supportive care is "*not restricted to dying patients nor to cancer*" but should cover the support of patients with a variety of long-term conditions. The National Council for Palliative Care (NCPC) (2009) embraced this broader approach to supportive care saying that "*Everyone facing life-threatening illness will need some degree of supportive care in addition to treatment for their condition*". They therefore proposed the following definition of supportive care for people with any life-threatening condition:

> *"Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment*

and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment." (National Council for Palliative Care 2009*)*

Ahmedzai (2005) made the case for expanding supportive care and said that by adopting this broader view of supportive care, "*the possibility of a truly humane, holistic and respectful system of care becomes possible for patients at any stage of disease, with any serious illness*" (p.16). This was backed up in the World Health Organisation's (WHO) publication on Palliative Care (2004, p.12) which reported that the needs and concerns for those experiencing non-cancer illnesses are comparable and possibly greater to those with cancer at some points in the illness. Ahmedzai and Walsh (2008, preface) drew attention to the fact that supportive care is increasingly recognised as a "*modern response to complex disease management*" but that there is little dedicated literature in this field.

Despite the ambiguity highlighted earlier, more recent literature does seem to be reaching agreement as to the elements that effective supportive care should include (NCPC, NICE, WHO), with the NCPC (2009) listing the following elements to supportive care; self help and support, user involvement, information giving, psychological support, symptom control, social support, rehabilitation, complementary therapies, spiritual support, palliative care and end-of-life and bereavement care. On examination of these elements, there is a close fit between these elements and the aspects of social support described earlier. For example, information giving maps to informational support, tangible support could take the form of medical care to control symptoms as well as the provision of complementary therapies and emotional support has close association with psychological support. Therefore, the use of Schaefer et al's (1981) concepts of social support to inform the types of support provided by professionals could be seen to have a close fit with supportive care.

3.8   Self-Care Support

Another strand of evidence appearing in the "support" literature is that relating to self-care support and self-management support. These two terms appear to be used interchangeably with little apparent difference between the two. Self-care is explained by the Department of Health (2006, n.p.) as being about

"individuals taking responsibility for their own health and well-being (including) staying fit and healthy ...; ... the better use of medicines; ... and better care of long term conditions".

Making the case for self-care support, the Department of Health (2005b) outlined how people want more information, choice and control over their lives including their health and reports that patients and the public have said they want more support to self-care. As well as this increasing expectation of the public, they also highlighted an increasing demand on health services from people with longer term health needs (over 15 million people in England) (Department of Health 2006). Patients with long term conditions can be broadly divided into three groups requiring different levels of support, with the large majority (70-80%) being able to manage their own conditions given the right support (Department of Health 2004a). The policy emphasis for this majority group is one of self-care support, which despite being described as a "real option", does not appear to be clearly defined in any of the relevant policy documents (Department of Health 2005b and Department of Health 2006). Instead, diagrammatic representation of supporting self-care across the whole system is used to demonstrate its component parts. This is shown below in Figure 1.

Figure 1: Self care

Supporting self care across the whole system

Self care for maintenance of good health and lifestyle and prevention of ill health

Self care of minor ailments

Professional care of minor ailments

Self care of long term conditions

Professional care of long term conditions

Self care of acute illness

Professional care of acute illness

Self care support
- Patient education
- Self care skills training
- Health & social care information
- Care plan approach
- Self diagnostic tools
- Self monitoring devices
- Peer support networks
- Home adaptations

(Department of Health 2006, p.12)

Once again, mapping these elements of self-care support against the tri-dimensional framework of social support demonstrates a close match. Education, training and information fit the aspect of informational support and tangible support is addressed through self-monitoring devices and home adaptations. However, it is not clear from the diagrammatic representation above, where and how the issue of emotional support is addressed. A summary of evidence collated by the Department of Health (2007b) looking at effectiveness of self-care included studies which contained a psychological element such as relaxation, self-care of stress, cognitive behavioural therapy, psychological support and other psychological interventions and therefore it is not clear why the above model excludes such support.

With such a policy emphasis on supporting self-care, it is clearly important to understand the nature and type of support that individuals require from health care professionals to assist them with managing their own condition. Looking at empirical evidence to inform an understanding of professional support for self-care and management, it is worth highlighting the work of Thorne and Paterson (2001, p.81) who reported that direct support from health professionals is "*rarely considered by researchers to be among the important elements of effective support*". However, they also made the point that research investigating the subjective understanding of people who live with chronic disease does demonstrate the supportive function of health care relationships as a critical factor in the way an individual manages their condition (Thorne and Patterson 2001). They reported on their study with patients with diabetes and highlighted the power and importance of informational, emotional and instrumental (tangible) support from health care professionals, despite the fact that they were not focusing on health care relationships in their study.

Looking in more detail at the relationship between health professional and patient and its importance in self-care support, it is important to acknowledge the type of role this would necessitate from a professional perspective. Szasz and Hollender's (1956) model of mutual participation where the doctor helps the patient to help himself was proposed as "favourable", "realistic" and "necessary" in the management of most chronic illnesses, where *"the treatment program is principally carried out by the patient"* (p.57). They introduced the concept that the patient's own experiences provide "*reliable and important clues for therapy*" (Szasz and Hollender 1956, p.57),

a theory which is developed further by Tuckett et al (1985, p.79), who stated that "*in certain respects the patient has a greater expertise than the doctor*".

More recently, Farrar (2009) has reiterated this concept by describing the individual with having expertise about themselves and the doctor with expertise on medicine and health intervention. He highlighted the need for the traditional doctor-patient relationship to change to support patients to manage their own condition. However, Koch et al (2004) examined self-care for patients with asthma and identified three models of self-management in chronic illness; medical model, collaborative model and self-agency model but they found that a medical model was the most common where the doctor gave orders and the patient followed them. It is reinforced further by Thorne et al's work (2000) with patients with chronic illness which showed that the health professionals had "*little appreciation for those aspects of illness beyond the realm of what biomedical science makes rational*" (p.306).

Wilson et al (2006) also identified this biomedical approach by health professionals as an issue when investigating the relationship between nurses and active and informed patients. The authors found that nurses expressed "*feelings of discomfort with expert patients*" (Wilson et al 2006, p.808) with the majority of nurses uncomfortable about being challenged by knowledgeable patients. Patients expressed that meeting their emotional needs was a clear area of nursing expertise but non specialist nurses expressed a more biomedical approach describing patients who focused on the emotional consequences as difficult. A subsequent paper by Wilson et al (2007) explored this issue further and described how many expert patients learnt not to discuss emotional needs in encounters with health professionals but kept to strict biomedical boundaries.

Hupcey and Morse (1997) described the nature of the relationship between the provider and recipient of support and the impact of role expectations as a key factor in creating differences between professional and social support. From the self-care literature described, it would seem apparent that there is a need to change role expectations away from the more traditional biomedical approach to the professional/patient relationship in order to achieve successful self-care of long term conditions, with patients being able to identify their support needs and professionals able to respond accordingly.

3.9 Summary

The self-care literature and that describing supportive care reinforce the importance of healthcare professionals providing appropriate support to people with long term conditions. However they add little additional detailed knowledge regarding the components of professional support although they do support the types of support making up the proposed framework of professional support as outlined earlier. This tri-dimensional framework of professional support, consisting of emotional, informational and tangible support will therefore be used as the theoretical framework underpinning this study.

4 Overall Methodology for Study

The overarching aim of this study was to identify and examine the professional support needs of patients with atrial fibrillation. As previously described, there is little evidence to describe the concept of professional support, none of which is specific to AF. In addition, there is little information describing the experiences of people with AF which might have provided some indications to the professional support needs of this group. Therefore, in order to carry out this research, both qualitative and quantitative components are required and a mixed methods approach was adopted.

4.1 Mixed Methods and Pragmatism

Tashakkori and Creswell (2007) define mixed methods research (MMR) as:

> *"research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry" (p.4)*

Burke Johnson and Onwuegbuzie (2004, p.15) visualise MMR as a:

> *"continuum with qualitative research anchored at one end and quantitative research anchored at the other, (with) mixed methods research covering the large set of points in between"*

They propose that its goal is not to replace qualitative or quantitative approaches but to "*draw from the strengths and minimize the weaknesses*" of these approaches.

Criticism of MMR focuses on the different epistemological commitments of qualitative and quantitative research methods and a belief that these are two separate and discrete paradigms (Bryman 2004) which Howe (1988, p.10) calls the "*incompatibility thesis*". Howe (1988) disagrees with this and takes a pragmatic approach to support his proposed compatibility theory by suggesting that quantitative and qualitative methods are "*inextricably intertwined*" (Howe 1988, p.13) due in part to the fact that the quantitative-qualitative distinction between data is "ambiguous" (Howe 1988, p.11).

Feilzer (2009, p.3) supports this notion and highlights that quantitative and qualitative methods "share many commonalities in their approaches to inquiry". Onwuegbuzie and Leech (2005, p.379) expand this by proposing that there are "overwhelmingly more similarities between quantitative and qualitative

perspectives than there are differences". They highlight how both use observations to collect data, build in safeguards, carry out analytical techniques to reduce the data and include verification process. Sechrest and Sidani (1995) suggest that although there are differences in philosophical assumptions and the ways in which data is collected and analysed, the ultimate aims of qualitative and quantitative researchers are the same, to:

> *"describe their data, construct explanatory arguments from their data, and speculate about why the outcomes they observed happened as they did"* (Sechrest and Sidani 1995, p.78*)*

This notion of a common approach to research is summarised by Onwuegbuzie and Leech (2005, p.381) saying that "*regardless of orientation, all research in the social sciences represents an attempt to understand human beings and the world around them*". The rejection of the "either-or choices from the constructivism-positivism approach debate" is proposed by Teddlie and Burke Johnson (2009, p.73) as one of the main reasons for pragmatism being the "philosophical partner of choice" for MMR.

Pragmatism is defined by Tashakkori and Teddlie (2003, p.713) as:

> *"a deconstructive paradigm that debunks concepts such as "truth" and "reality" and focuses instead on "what works" as the truth regarding the research questions under investigation. Pragmatism rejects the either/or choice associated with the paradigm wars, advocates for the use of mixed methods in research, and acknowledges that the values of the researcher play a large role in the interpretation of results."*

This view is supported by Feilzer (2009, p.3) who proposes that pragmatism "*side steps the contentious issues of truth and reality*", accepts that there are singular and multiple realities and is focused on solving practical problems in the real world. Felizer also proposes that pragmatism does not exclude any particular research and does not expect "*to find unvarying causal links or truths but aims to interrogate a particular question, theory, or phenomenon with the most appropriate research method*" (2009, p8).

This concept of the most appropriate method for the research question is fundamental to pragmatism and Bryman (2006, p.118) describes this as the "centrality" of the research question. He maintains that that the "crucial arbiter" of adequacy of methods for answering research questions should guide which methodological approach should be adopted as opposed to commitment to a paradigm or philosophical doctrine. Tashakkori and Teddlie (2003) include the primary importance of the research question as one of key arguments for linking pragmatism with MMR and Creswell and Plano Clark (2007) highlight the primary importance of the question asked rather than the methods as one of the key worldviews of pragmatism. They describe pragmatism as "*pluralistic and oriented towards "what works" and practice*" (Creswell and Plano Clark 2007, p.23).

Armitage (2007, p.3) says that taking a pragmatic "what works" tactic allows the researcher to answer questions that may not fit exactly between a wholly qualitative or quantitative approach to design and methodology. In a similar vein, O'Cathain et al (2007) outline MMR in health care and highlight the fact that researchers feel the need for a range of methodologies to understand and evaluate the complexity of health care. Halcomb et al (2009) reinforce this finding by proposing that a multifaceted approach must be taken in health care research due to the multifaceted nature of the phenomena being investigated and that MMR offers an appropriate methodological framework.

Continuing in the theme of health care, it is of interest for this study to note the work of Scott and Briggs (2009) who propose that the practice of medicine is a prime example of pragmatism and therefore a pragmatic approach is required to research in this field. One example they use to support this theory is that of clinical knowing and how clinicians will mix qualitative data (patient narrative, colleague opinion, personal experience) with quantitative data such as test results, vital signs and physical examination (Scott and Briggs 2009, pp.232-233).

Given the complexities surrounding professional support described in the literature section, it is clearly a multifaceted phenomenon. This study requires an approach which will facilitate both the identification of need from the perspective of participants and the development of a tool with clinical utility which would be best addressed using both qualitative and quantitative research methods through MMR.

When designing a MM study, commentators highlight there are several aspects that influence the design. Morgan (1998) describes the need for a priority decision and a sequence decision. Creswell and Plano Clark (2007) expand this to three factors; the timing decision, the weighting decision and the mixing decision. Creswell (2009) develops this even further by adding a fourth aspect, theorising or transforming perspectives, to those detailed by Creswell and Plano Clark (2007)

Looking in more detail at each of these aspects, sequential designs are described by Teddlie and Tashokkori (2009, p.153) as when "*The conclusions based on the results of the first strand lead to the formulation of design components for the next strand*". This has an obvious fit with instrument development and therefore it is clear that for this study, the sequence/timing decision is straightforward as the phases must be sequential in order for the qualitative work to inform the development of the questionnaire.

Creswell and Plano Clark (2007, pp.83-4) describe mixing as "*the explicit relating of the two data sets*"; without it a study that includes both quantitative and qualitative methods is "*simply a collection of multiple methods*". Three different strategies exist for mixing: merging/integrating, embedding and connecting. Connecting occurs "*when the analysis of one type of data leads to (and thereby connects to) the collection of the second type of data*" (Creswell and Plano Clark 2007, pp.83-4) and is therefore the obvious strategy of choice for this study.

The weighting (or priority) decision determines the extent to which either the qualitative or quantitative research is the principal tool for the research (Morgan (1998, p.366). Although Morgan (1998) describes giving the two methods equal priority as "often impractical", other authors (Creswell and Plano Clark 2007 and Creswell 2009) say the weight can be equal. Morgan (1998) proposes the use of the research goals as the mechanism to select a principal data collection method and Morse (1991) suggests that the theoretical worldview of the study determines the weighting, with pragmatism calling for an equal or unequal weighting depending on the research question. Although Creswell (2009) and Creswell and Plano Clark (2007) both describe that in instrument development the weighting is usually qualitative, both Bryman (2008) and Teddlie and Tashakkori (2009) say that it is often not possible to determine the relative importance of each of the components of

the study before it begins. Teddlie and Tashakkori (2009) say that in the real world, the emphasis may change, depending on which set of data becomes more important in understanding the phenomenon under study. The overarching aim of this study was to identify and examine the professional support needs of patients with atrial fibrillation, with specific objectives relating to both the qualitative and quantitative phases and so therefore the initial decision relating to weighting was that each should be given an equal weighting.

Finally, Creswell (2009) describes the need to consider whether a theoretical perspective guides the entire design and that this may be explicit or implicit. He describes the explicit theories typically found in mixed methods studies as an "*orienting lens that shapes the types of questions asked*" (Creswell 2009, p.208) as well as influencing the selection of participants, data collection and implications made from the study which are typically for change and advocacy. He also proposes that for a sequential – qualitative first study, theorising may be either 'explicit or implicit' (Creswell 2009, p.207). However, Teddlie and Tashakkori (2009, p.140) state that this "*pursuit of social justice*" is not a design choice but it is the reason for doing the research. Gorard and Taylor (2004) support this by saying that the use of mixed methods is a choice driven largely by the research question and not by the ideology of the researcher.

Although this study has a clear theoretical framework of professional support, the use of mixed methods has been chosen as the most appropriate to address the research question, with the desire to see all people with AF receiving the professional support that meets their need as the reason for doing the research (rather than influencing the design).

4.2   Mixed Methods and Instrument Development

Kroll and Neri (2009) postulate that insufficient information available in the literature and therefore a need for exploratory research is a reason for choosing mixed methods rather than what they describe as "'*traditional' designs*" (2009, p.32). This is supported by Creswell (2009) who states that mixed methods is a recognised methodology for development of quantitative instruments and calls it the "*procedure of choice*" when existing instruments are "*inadequate or not available*" (p.212). Tritter (2007, p.302) highlights that explicit questions and hypothesis developed in an initial

qualitative phase can "*yield the key dimensions which can then be used to frame a later stage of the project which will adopt other methods*". Bryman (2008) supports this view saying that the in-depth knowledge of social contexts acquired through qualitative research can guide the development of more quantitative tools.

Tritter (2007) highlights the importance of understanding the experience of a target population by stating that "*Research that builds on the health needs expressed by a population group being studied is especially relevant when the object is to evaluate or develop a health service*" (p302). This is of particular importance in this study to achieve the objective of contributing to the evidence base and improving patient experience.

Onwuegbuzie et al's (2010) article on the use of mixed research as a tool for developing quantitative instruments describes instrument fidelity as "*steps taken by the researcher to develop an instrument and to maximise its appropriateness and/or utility*" (*p*59*).* They highlight that instrument fidelity *"lacks adequate development*" with scant guidance for researchers and believe that this is likely to stem from the perception that the development of instruments occurs within the same methodological tradition. They therefore identify a need for more publications explicitly outlining ways of optimising instrument development by mixing qualitative and quantitative techniques.

Williams et al (2004) propose the use of qualitative research to investigate what social support means to the group being studied as this will allow confident measurement of the role of social support in certain contexts, rather than a quantitative approach which they feel will "*necessarily be influenced and constrained by the researcher's understanding of the concept of social support*" (Williams et al 2004, pp.957-8). This is supported by Tritter (2007 p.302*)* "who state *"This type of approach can ensure that research is grounded in the experience of those who are the object of the study*".

Similarly Onwuegbuzie et al (2010) propose that it is important to ensure that the voices of those on whom the instrument will be administered are heard "*with a view to understanding their cultural milieux*" (p.63) and advise that individual interviews can play an important role. This is supported by McColl and Thomas (2000) who advise that members of the target audience should be consulted to ensure that the

researcher is familiar with the typical vocabulary of the subjects of the survey, ensuring that the questions are worded appropriately.

Such an approach has already been used in the cardiology field by Davidson et al (2004) who used this approach for patients with heart failure, carrying out interviews to identify their supportive care needs and from there, developing and using the heart failure needs assessment questionnaire. Her questionnaire has then been used to assess unmet need for patients who had been admitted with heart failure and to assess the impact of an intervention designed to address these needs.

4.3   Overall Study Design

Given the lack of information regarding the professional support needs of people with AF and the recognition of mixed methods as an appropriate approach for studying health care, an exploratory sequential design was therefore chosen (Creswell 2009) to explore the views of participants with the intention of using this information to develop and test a quantitative instrument which could then be used to assess the professional support needs of patients with AF.

Figure 2: Diagrammatic plan of exploratory sequential design
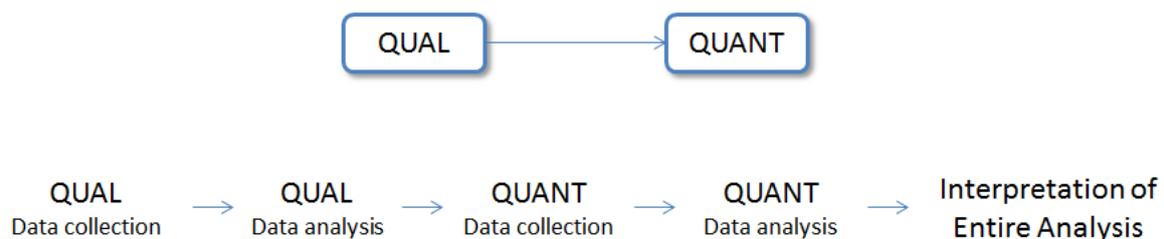
Adapted from Creswell 2009, p.209

As the study is a sequential design with the findings from the initial qualitative phase informing the content of the quantitative phase, the qualitative phase is reported together with the findings from this phase. The quantitative phase is then described together with its associated findings followed by interpretation of entire analysis.

4.4　Public and patient involvement in research

4.4.1 Background

Government policy has advocated the involvement of public and patients in health research over and above participation as research "subjects", with the national research governance framework stating "*Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research".* (Department of Health 2005c, p.8) INVOLVE is a government funded programme to support active public involvement in NHS, public health and social care research and describes involvement in research as "***active involvement between people who use services, carers and researchers, rather than the use of people as participants in research"*** (INVOLVE 2004). When describing public involvement, there are differences in definitions of the term "public" with INVOLVE using the terms shown in Table 4 below.

Table 4: Definition of the term "the public"

When talking about 'the public' INVOLVE means:
- patients and potential patients   - people who use health and social services   - informal (unpaid) carers   - parents/guardians   - disabled people   - members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions   - groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos)   - organisations that represent people who use services.

INVOLVE 2006 p3

Using a similar approach to INVOLVE, in this study the term "public" will be used to describe patients and potential patients, people who use health and social services and organisations that represent people who use services, including established

user groups for patients with cardiac conditions and charities such as the Atrial Fibrillation Association (AFA)[4].

In addition to the goals of public accountability and transparency (Nilsen et al 2006), the involvement of patients/public is believed to lead to higher quality research of more clinical relevance (Boote 2002 and INVOLVE 2004) and also to a greater uptake in findings (Whistock 2003). Brett et al (2012) propose that the improved quality is due to the unique perspective that users can bring to the research project. This is supported by INVOLVE (2006) who highlight that public involvement brings "*knowledge and experience of a particular condition or service relevant to the research topic*".

Boote et al (2002) propose that the consumer perspective in health care is important as it complements that of the clinician and the researcher. They highlight the important of distinguishing between disease (described as a physiologic and clinical abnormality) and illness (the subjective experience of the individual) and go on to say that when the consumers' perspectives on illness are combined with the clinicians' interests in disease "*a synergistic relationship can exist and new insights can be gained to improve the condition of the consumer*" (Boote et al 2002, p.218). This is supported by Hewlett et al (2006, p.676) who propose that the personal experience of disease of patients "complements researchers' analytical skills and scientific perspective" and also by Brett et al (2012, p.9) who highlight that the service users' role is "equal but different" to researchers. They propose that it is this "*unique perspective of the lived experience of the condition under investigation*" that brings added value.

Stewart and Liabo (2012) advocate that health knowledge comprises not just of expertise gained through research and medical practice, but also from the expertise that patients have gained by living with an illness and receiving treatment. Collins and Evans (2002, p.5) describe someone who has expertise as a result of experience as an "*experience-based expert*" and propose that they have a significant role to play in the development of knowledge and understanding. This notion of the expertise of patients has a close fit with the theories described the section "Self-Care

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[4] More information on the AFA is available on page 104 and at http://www.atrialfibrillation.org.uk/

Support" (page 54 onwards) relating to patients as experts in their condition and the idea of a partnership approach to management of their condition.

In a similar vein to this partnership approach of different expertise of clinician and patient, Stewart and Liabo (2012) propose it is important to ensure that there is a range of different expertise involved in order to execute relevant, rigorous and influential research. They propose that different expertise is more relevant at different stages of research: Patients and the public have expertise of health, illness and receiving treatment so their expertise enables them to identify research topics, questions, interventions and outcomes of importance whereas researchers have the technical expertise essential for rigorous research.

This research study has taken a mixed methods approach to ensure that the voice of patients is integral to the study. As described in the overall methodology chapter (page 59 onwards), the use of qualitative research to inform the development of the questionnaire ensures that the research is "*grounded in the experience of those who are the object of the study*" (Tritter 2007, p.302), reflects the "*typical vocabulary*" of the subjects of the survey (McColl and Thomas 2000, p.15) and has an understanding of the "*cultural milieux*" of the study population (Onwuegbuzie et al 2010, p.63). This has a close fit with the model proposed by Stewart and Liabo (2012) promoting the use of public expertise at the stage of identifying research topics and questions.

Throughout the design and development of this study, public involvement has played a key role to ensure the perspective of people with AF has guided the study. At different stages of the study, various approaches were taken to ensure that there was appropriate public involvement and to ensure that this involvement was used to inform the development of the study. These approaches are described throughout the methodology of the study and are grouped together in more detail in the Quality chapter (at page 187) to illustrate how public involvement has influenced and informed the research.

5 Methods - Initial Qualitative Phase

To generate the information to support the development of the quantitative instrument, individual interviews were chosen. Mack et al (2005) highlighted that interviews are especially appropriate for addressing sensitive topics that people might be reluctant to discuss in a group setting. This was felt to be an important consideration as participants would be asked to identify positive and negative experiences of their encounters with health care professionals.

Bryman (2008) suggests that interviews allow for flexibility to allow the study to respond to the direction in which interviewees take the interview and if necessary to adjust the emphases in the research as a result of significant issues that emerge in the course of interviews. This was felt to be of particular importance in this study given the lack of literature available in this field prior to the interviews commencing.

A topic guide for the interviews was designed to encourage participants to express their experience in their own words and so asked them to describe what it has been like living with their irregular heartbeat. (See Appendix B: Interview Topic Guide) Questions were included to identify the classification and duration of atrial fibrillation. In addition, questions used in the work detailed earlier relating to the specificity of social support were included to begin a more in-depth exploration of the types of support that people would like to receive from their health professional. These questions relating to most helpful and least helpful support and specificity of support were included to allow comparison with findings from the few previous studies including an element of investigation of professional support (Dakof and Taylor 1990; Martin et al 1994; Warwick et al 2004; Boutin-Foster 2005 and Masters et al 2007;). Therefore, participants were asked "*Thinking about the health care professionals you have seen, what has been the most helpful thing that any of them have said or done to help you with your irregular heart beat*?" and "*Thinking again about the health care professionals you have seen, what has been the least helpful thing that any of them did or said, or something that rubbed you up the wrong way*?"

The topic guide was shared in a draft format with a cardiac patient group[5] which the author was involved with through a work capacity who suggested a need for tighter questions to avoid "rambling". Their use of the specific word "rambling" is of interest as it is also used by Bryman (2008, p.437) discussing interviews. However he states: "'*rambling' or going off at tangents is often encouraged as it gives insight into what the interviewee sees as relevant and important".* Given the purpose of the interviews was to generate information, the topic guide therefore remained unchanged despite the suggestion of the patient group.

5.1　Participants

Participants were recruited from outpatient arrhythmia clinics at an acute healthcare trust in South London. In line with criteria for other studies of patients with AF, inclusion and exclusion criteria were applied as shown in Table 5 below.

Table 5: Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
- Adults over the age of 18 with atrial fibrillation	- Adults whose AF was due to secondary causes (such as post-operatively, hyperthyroidism), - Adults who could not read or understand English, - Adults who had had a previous cardiac event (such as a myocardial infarction or cardiac surgery) in the last six months

Patients were selected from those seeing a consultant cardiologist specialising in atrial fibrillation and those seeing arrhythmia nurse specialists (ANS) in order to provide a comparison between those patients who saw the ANS and those who didn't.

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[5] For more details of the cardiac patient group, please see the section on public and patient involvement (Page 63)

5.2 Sampling

A strategy of purposive sampling was planned in order to explore issues relating to professional support in people with AF. The aim was therefore not to represent the overall population of people with AF but rather to gain a more detailed picture of the phenomenon of professional support. Bryman (2008, p.458) describes purposive sampling as trying to ensure there is a "*good correspondence between research questions and sampling*" which fits with Palys (2008, p.697) who says that "*the way that you sample has to be tied to your objectives*". It was important to ensure a spread of age, gender, contact with an arrhythmia care coordinator and classification of atrial fibrillation as all these factors could influence professional support needs therefore, maximum variation purposive sampling was planned to try and gain an understanding of the impact these factors had on professional support needs. It was recognised that the exclusion criteria relating to English language meant that maximum variation sampling did not include people who did not read or speak English who may have different support needs to the population of this study. However, as translation/interpreter services were not available to the study, inclusion of this group was not practical and this could be an area where further research is needed in the future. Purposive sampling in this way has a close fit with the pragmatic "what works" approach described earlier (Tashakkori and Teddlie 2003 and Armitage 2007).

It was envisaged that this sampling would be achieved with between twelve to fifteen interviews. Whilst this may be smaller than some other qualitative studies, the findings from this study were used to inform a larger quantitative study to explore the issue of professional support within a larger sample of atrial fibrillation patients. Therefore this number of interviews was felt to be adequate to inform and direct the larger study whilst remaining feasible within the scope of a DHRes project.

5.3 Ethical Issues

Silverman (2010) highlights that whilst codes of research ethics vary across disciplines and national boundaries, there are five main general principles to be addressed in order to protect participants. Table 6 shows how these were addressed in the study.

Table 6: Ethical Principles and how these were addressed in qualitative phase of study

Ethical Principle	How addressed in study
Voluntary participation and the right to withdraw	Only the details of those people who expressed an interest in participating were passed to the researcher.
	The information sheet detailed that there would be no impact on medical care should the participant chose either not to participate or to withdraw from the research.
	When the researcher contacted the potential participant, the fact that participation was voluntary was reinforced.
	The consent form specifically highlighted that participation was voluntary and that participants could stop and/or withdraw at any stage.
	Participants who appeared upset during the interview were asked if they wished to stop or continue.
Protection of research participants	Patient identifiable information was only released to the researcher by the clinical team when the patient had expressed an interest in participation.
	Participants were given a choice of location for the interviews to take place, either at their own house or the hospital.
	Audio recording devices were only used to record the interviews when the participant consented to this.
	Personal data was stored on an NHS secure server. Access to the data was restricted to the Chief Investigator and for additional security, files was password protected. The database containing personal data was stored in line with the NHS Trust's Information Governance Policy.
	Personal data was stored in line with Department of Health guidance for retention of medical records and will be destroyed in line with Department of Health guidance.
	Participants in the study were allocated a unique identifier which was used in transcribing and analysing of data.
	All identifiers mentioned by the participant or researcher during the interview were also anonymised so that it was not possible to identify an individual or location from the transcript.
	Although direct quotations from respondents may be published in reporting the findings of this study, these will be anonymised and care will be taken to ensure that identification of individuals is not possible.

Ethical Principle	How addressed in study
Assessment of potential benefits and risks to participants	Potential risks and benefits were assessed and outlined as part of the REC application (see Appendix C1: Application form). The study may not directly benefit participants themselves, however the information from this study will help improve the care of people with an irregular heartbeat, leading to an improved service for patients. The main disadvantage for participants was the time element required to take part in the interview. There was also the potential for patients to become upset during the course of the interview as they relived their experiences of their condition. The research design was reviewed by an external patient group who indicated that they felt it was important for healthcare professionals to learn more about the experiences of this group of patients and felt that the time commitment for interview participants was an acceptable burden to ensure this was achieved.
Obtaining informed consent	Each participant was sent an information sheet before agreeing to participate. The information sheet detailed the purpose of the research, the lead researcher and the organisations involved as well as addressing potential risks and benefits to participation. It also outlined that participants had been identified from the arrhythmia outpatient clinic. Participants were asked to complete a consent form before the interview took place. The form specifically highlighted the issues of voluntary participation and right to withdraw outlined above. In addition, participants were specifically asked to consent to the audio recording of the interview and the transcription. As part of the consent process, participants were also asked if they wanted to review the transcript of their interview before it was analysed.
Doing no harm	Maintaining confidentiality of participants is important to ensure no harm. As detailed earlier, identifiable information was removed from transcripts and care taken to ensure patients could not be identified from direct quotes. This was particularly important as participants were being asked to recount examples where they felt they had received unsupportive care from health care professionals which could have ramifications for their care moving forwards. In addition, the ethics application detailed how the researcher would act if participants became distressed or upset whilst the interview was taking place; in such cases, the researcher would offer to pause or stop the interview.

As the research involved NHS patients, an application was submitted through the National Research Ethics Service and was reviewed by the local Research Ethics Committee (REC). Ethics approval was granted following minor amendments to the initial application. Full details of the application including the protocol can be seen in Appendix C: Ethics Application – Qualitative Phase.

5.4   Access

In this study, the clinical team acted as gatekeepers, restricting access to potential participants by the researcher. If patients attending clinic met the inclusion criteria, members of the clinical team outlined the research, provided the patient with an information sheet and agreed to share the potential participant's contact details with the researcher. The researcher was then able to contact the potential participant and arrange how to proceed. This process is detailed in Figure 3 overleaf.

Figure 3: Proposed flow chart

Flow chart boxes (top to bottom):

- Patient attends outpatient arrhythmia clinic
- Member of clinical team identifies that patient matches inclusion criteria and asks if patient would be interested in participating in study
- Patient given information sheet and asked if they are interested in participating
- Details passed to researcher and sampling carried out to select participants
- Selected participants sent invitation letter, information sheet and stamped addressed envelope and asked to return to indicate if wiling to be interviewed
- Interview arranged at participant's home or hospital depending on preference
- Participant asked to complete consent form before interview begins
- Interview completed

No further action

→ Positive outcome

→ Negative outcome

After three months of using the study protocol, no patients had been identified to take part in the study. Discussions with clinicians highlighted a lack of time during clinical consultations to follow the required stages.

Patterson et al (2011) highlighted that the process of trials can be affected when potential participants' capacity to be invited into a study is inhibited by others and this was definitely an issue for this study. There were a variety of reasons that could have caused this in the current study: the arrhythmia nurse specialists were relatively new in post and so recruitment into the study would have been an extra demand on their time and potentially they felt unsure about obtaining consent for participation; there was a significant increase in referrals into arrhythmia clinics, adding to demands on clinicians' time and also it is possible that the aims of the study had not been clearly explained so clinicians could not see the benefit to them of recruiting. These clearly relate to the barriers in clinician participation in research that have been highlighted by Prescott et al (1999). In addition, the centre began to take part in a large international multicentre randomised control trial for AF which it is suspected took preference for recruitment during clinical appointments.

Due to the nature of the author's job role, access to potential participants was not possible and therefore there was a reliance on others to recruit to the study. Charlson and Horwitz (1984) identify potential selection bias can be introduced into research by 'gatekeepers' and it is clear that this is a factor that will influence the potential ability to generalise the findings from this study to the wider AF population. However, it will provide an indication as to the support needs of patients attending outpatient arrhythmia clinics.

An amendment was therefore submitted to the Wandsworth REC to allow the clinicians to identify patients after their clinic and to send out invitation letters to patients who met the inclusion criteria who were felt to be appropriate to participate. People who then completed and returned the reply form would then be contacted by the chief investigator as previously planned. This would allow participants to be identified and invited to participate by the clinical team without impacting on patient contact time in clinics. (For details please see Appendix C7: Amendment submission to ethics).

Patient attends outpatient arrhythmia clinic

After clinic appointment, member of clinical team identifies that patient matches inclusion criteria

Selected participants sent invitation letter, information sheet and stamped addressed envelope and asked to return to indicate if wiling to be interviewed (n=30)

People complete and return reply form indicating willingness to participate (n=16)

Participants contacted by researcher to confirm willing to participate interview (n=15)

Interview arranged at participant's home or hospital depending on preference (n=14)

Participant asked to complete consent form before interview begins (n=14)

Interview completed (n=14)

No further action

Positive outcome

Negative outcome

The revised approach did lead to participants being recruited to the study with thirty people being identified by clinicians as suitable to participate. Taking the pragmatic "what works" approach, given the small numbers identified, no sampling took place and all people identified by clinicians were sent an invitation to participate. There was a good response rate to the invitation to participate (57%), with seventeen people replying; sixteen who were interested in taking part and one who felt that his story would be of little interest to the study. Interviews were arranged with fifteen of the sixteen respondents with one person being uncontactable despite repeated attempts. Four respondents chose for their interviews to take place in a hospital setting and eleven in the home. However, one "home" participant was admitted to hospital on the day before the interview so a total of fourteen interviews were completed. Numbers of participants at each stage of recruitment are shown in Table 7 below.

Table 7: Numbers of participants at each stage of recruitment

Stages of recruitment	Numbers of participants at each stage
Identified by clinicians and sent invitation to participate	30
Responded to invitation	17 (57%)
Declined to participate as felt story would be of little interest to the study	1
Unable to contact to arrange interview	1
Taken ill on day of interview and unable to participate	1
Total number of interviews carried out	**14**

Although the small numbers responding to the invitation to participate meant that maximum variation sampling did not take place as planned, there was actually a spread of age, gender and classification and duration of AF across participants. For more details of participant demographics see section 6.1 (Participants).

5.5   Data Collection

As part of the consent process, at the beginning of the interview all participants were offered the opportunity to receive a copy of the transcript of their interview and to comment on any inaccuracies. Eleven of the participants (79%) requested the transcripts which were sent after the interview; there was no feedback from any of

these participants which suggests they were happy that the transcript provided an accurate account of the interview as experienced on that day.

Interviews ranged from 45 – 90 minutes duration and all participants gave their consent to the interview being audiotaped. The interviews began with the question "*tell me what it has been like living with AF*" to allow participants to describe their experience of AF. In addition to audio recording, field notes were taken during the interview to ensure non-verbal responses were recorded. The interviewer also added to these field notes once they had left the interview to record thoughts and feelings for future reference.

The interviews were transcribed verbatim as soon after the interview as possible with identifiable information replaced by pseudonyms. The transcripts were then re-read to see if there were any areas of support arising that had not previously been covered by the topic guide. Using an iterative approach, after the first two interviews where both respondents highlighted physical activity and exercise as a specific issue, questions on this topic were added to the interview schedule to discover more about the views of people with AF. During these first interviews, participants mentioned the fact that they had changed their levels of physical activity as a result of their AF. Given the apparent similarities to the fear avoidance beliefs Waddell et al (1993) identified in people with chronic low back pain, it was felt important to investigate this issue further in subsequent interviews.

5.5.1 Fear Avoidance Beliefs

Waddell et al (1993) developed the Fear Avoidance Beliefs Questionnaire (FABQ) for use in people with low back pain and this has predominately been the field in which it has been used to date (Williamson 2006). However, Roaldsen et al (2009) used the physical activity subscale of the FABQ (FABQpa) with leg ulcer patients and demonstrated that "*strong fear-avoidance beliefs may lead to low physical activity in patients with chronic venous disease*" (2009, p.178). Furthermore, in the arrhythmia specific field, Ittersum et al (2003) used the FABQ in their study aiming to describe health related quality of life (HR-QoL) and fear of exercise in patients receiving an implantable cardioverter defibrillator (ICD). They found that a considerable number of participants reported fear of exercise and that this fear appeared to negatively influence health related quality of life (HR-QoL). They

concluded that "*appropriate rehabilitation and interventions should be considered in patients with a clear fear of exercise in order to optimize their HR-QoL*" (Ittersum et al 2003, p.121).

The FABQ consists of two subscales and assesses patient beliefs with regard to the effect of physical activity and work on their low back pain. It consists of two subscales; the work subscale (FABQw) and the physical activity subscale (FABQpa). Williamson (2006) reports that the FABQpa may be more appropriate for those people who don't work (p149) and as interview responses had indicated an impact on physical activity levels, it was decided to focus on the FABQpa. This would have the added benefit of being relevant for all participants irrelevant of employment status.

Elements of the FABQpa subscale were therefore modified accordingly for patients with AF and used during the remaining interviews to see these questions were relevant. All participants were asked if they thought they could not do physical activities as these (might) make their irregular heart beat worse. Those participants who raised the subject of physical activity during their interview were asked some of the additional statements, dependent on their accounts. This was to ensure that the overall interview was guided by the patient's experience rather than had an overemphasis on physical activity led by specific questions from the interviewer. The FABQ adapted questions were as follows:

1. Do you think that your irregular heart beat was/is caused by physical activity?

2. Do you believe that physical activity brings on an episode of your irregular heart beat (either at the time or immediately afterwards)?

3. Do you think that physical activity might harm your heart?

4. Do you think that you should not do physical activities which (might) make your irregular heart beat worse?

5. Do you think that you cannot do physical activities as these (might) make your irregular heart beat worse?

5.5.2 Completion of data collection

Initial analysis was ongoing throughout the process of data collection with emerging themes identified and coded. This meant that common themes were recognised as they arose through repetition in a number of interviews and highlighted that towards the end of the planned interviews, no new information relating to the research question was emerging. The penultimate participant (P114) did have a different experience to other participants but rather than changing the codes, this experience actually reinforced the developing codes and categories. Therefore, data saturation was considered to have been achieved once the interviews with all the participants had been completed, despite the small sample and it was not considered necessary to try and identify more potential participants. More detailed analysis was then completed (see section 5.6) to develop emerging theories and complete the analysis,

5.6 Data analysis

Creswell and Plano Clark (2007) and Creswell (2009) state that how data is analysed in mixed methods studies varies depending on the type of mixed methods design used (p135). Teddlie and Tashakkori (2009) support this by proposing their typology of mixed methods data analysis strategies based on design implementation processes. Therefore analysis for this sequential exploratory study needs to be of a sequential nature with the qualitative phase analysed before the quantitative phase begins in order to inform the development of the questionnaire.

Describing the mixed methods data analysis process, Onwuegbuzie and Teddlie (2003) identified seven stages: data reduction, data display, data transformation, data correlation, data consolidation, data comparison and data integration. In the overall study, four of the seven stages were incorporated, data reduction, data display, data comparison and data integration but for the initial qualitative phase, the major emphasis was on data reduction through the identification of themes, followed by data display to report the findings. The other stages are reported in the quantitative phase of the study. This use of data reduction is supported by Creswell (2009) who specifically describes the steps in data analysis for instrument development mixed methods studies as firstly to obtain themes and specific statements in an initial qualitative data collection and then use these statements and themes to create a survey instrument grounded in the views of the participants.

Therefore, the qualitative data collected during the interviews was analysed to identify the key themes relating to professional support needs. Each transcript was read and re-read several times before progressing to identify emerging themes and initial notes were made. Field notes were also read and re-read to ensure all relevant information was included in the analysis. Computer aided qualitative data analysis software (CAQDAS) was then used to manage the data and support the process of identifying themes. Both Bryman (2008) and Silverman (2010) summarise a range of concerns regarding the utility of CAQDAS, of which the most relevant to this study are the ease with which qualitative data could be quantified and fragmentation of data leading to a loss of context. Meethan (2010) also reports the criticism that CAQDAS will distance people from their data. However, Clare (2012) proposes that a CAQDAS package will assist researchers with the organisation and coding of data and can significantly speed up the process of tasks associated with qualitative research without compromising on quality. Both Clare (2012) and Meethan (2010) highlight that the use of CAQDAS will not necessarily improve the quality of the research and data analysis and that it still down to the researcher to "*think, deliberate, generate codes, reject and replace them with others*" (Clare 2012, p.11). The CAQDAS used in this study was MAXQDA[6].

Taking a pragmatic approach, Meethan (2010) highlights that researchers are likely to take what they can from the software and combine this with manual methods and this combined approach was adopted in this study for data analysis. The notes taken during initial reading and re-reading were used to create initial codes and then MAXQDA was used to support the "code-and-retrieve" stages of the analysis (Silverman 2010, p.253), with further codes added during the process. The choice of MAXQDA was a pragmatic decision; the researcher had undertaken training in how to use MAXQDA before beginning the research study and therefore had a basic knowledge and understanding of the software. Silver and Lewins (2009, p.4) describe MAXQDA as "*intuitive, simple and efficient*" and this was reinforced during the training which demonstrated that MAXQDA was capable of taking over what Bryman (2008, p.565) describes as the "*manual tasks associated with the coding*

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[6] MAXQDA is a type of CAQDAS for qualitative and mixed methods data analysis. For more information, see http://www.maxqda.com/

processes". As identified by Clare (2012), the actual process of coding data using MAXQDA was simply a case of highlighting the text and selecting which code to assign it to. In addition to the codes identified during the reading of the transcripts, responses were also coded using the framework of professional support based on the elements of social support: tangible, emotional and informational. This approach is line with other authors investigating social support with a qualitative approach (Dakof and Taylor 1990; Martin et al 1994; Masters et al 2007). Responses were carefully categorised to differentiate between those areas of support that participants identified themselves whilst describing their experiences of AF and those that were only discussed in response to direct questions from the researcher.

The use of MAXQDA allowed for one section of text to be assigned to several codes including those specific to professional support and then to be reviewed in the context of the overall transcript, thereby addressing the criticisms identified earlier regarding fragmentation and loss of context. Regarding quantification of qualitative data, this appears to have arisen from paradigm debates relating to the incompatibility of qualitative and quantitative data (Howe 1988) as some authors propose such quantification to be a useful approach to support understanding and explanation of findings (Unite for Sight 2011; Ward no date; Sauro 2012). Silverman (2010, p.286) also highlights how the use of simple counting techniques can give "*a sense of the flavour of the data overall*". Quantification was used to summarise responses to the most useful and least useful support provided by health care professionals, mirroring the approach of other authors investigating support (Dakof and Taylor 1990; Martin et al 1994; Masters et al 2007).

5.7   Quality

Although some authors propose that quality for mixed methods research can be assured by addressing data quality of each strand of the research, (Teddlie and Tashakkori 2009 and Giddings and Grant 2009), there is an emerging body of work that proposes the use of frameworks to address quality across all elements of mixed methods studies. Therefore, how this study addresses these issues of quality will be considered for the overall study as opposed to individual phases and these are described in more detail in Chapter 9 (Quality) after both the qualitative and quantitative phases have been described.

5.8 Summary

This chapter provides a detailed overview of the overall research approach together with the identification and selection of participants, ethical considerations, data collection and data analysis for the qualitative phase as well as introducing the issue of quality in MMR. Findings from the interviews are detailed in the following chapter and will then be used to inform the subsequent quantitative phase.

6 Findings from Qualitative Interviews

This section presents the findings from the interviews and locates them within the framework of professional support proposed earlier.

6.1 Participants

The fourteen participants consisted of eight men and six women ranging in age from 45 to 85 years old. Eight were white British and six from other ethnic groups. One participant had persistent AF, two permanent AF and the remaining eleven, paroxysmal AF (PAF). The duration of AF ranged from two months to twelve years with the average four years.

Table 8: Participant characteristics

Participant Number	Gender	AF classification	Duration of AF (years)
P101	Male	Paroxysmal	1.8
P102	Male	Persistent	0.2
P103	Female	Paroxysmal	1.8
P104	Female	Permanent	0.9
P105	Male	Paroxysmal	11.5
P106	Male	Paroxysmal	1.1
P107	Female	Paroxysmal	9.8
P108	Male	Paroxysmal	4.0
P109	Female	Paroxysmal	3.2
P110	Female	Paroxysmal	11.9
P111	Male	Permanent	8.9
P112	Male	Paroxysmal	2.9
P113	Unable to participate as admitted to hospital on day of interview		
P114	Male	Paroxysmal	4.3
P115	Female	Paroxysmal	5.0

Table 9: Classification and Ethnicity of Participants

Characteristic	Frequency
Classification (n=14)	
PAF	11
persistent AF	1
permanent AF	2
Ethnicity (n=14)	
White Irish	1
Chinese or other ethnic group Chinese	1
White British	8
White Other	2
Asian or Asian British Pakistani	1
Asian or Asian British Other	1

6.2   Initial signs and symptoms

Participants reported a range of signs and symptoms that led them to seek advice and support from health care professionals. For some participants, tiredness was the main symptom and an inability to do the things they had previously been doing and this led them to seek help. Others noticed varying degrees of palpitations or an irregular heartbeat. Two participants described the palpitations as being so bad they thought they were having a heart attack (P103 and P106) and therefore were admitted to the accident and emergency department (A&E). One described it as "*like I was sort of running a marathon for two days*" (P109) before calling their General Practitioner (GP) who told them to go to hospital, whilst others described their symptoms as "*a slight kind of fluctuation in my rhythm*" (P112) or "*an irregularity*" (P110). Symptoms presented in differing ways for individual participants and therefore initially tangible support was required from professionals in the form of medical assistance to achieve a diagnosis and explain and manage their symptoms.

6.3 Obtaining a diagnosis (Finding the meaning of symptoms)

Despite this initial need for tangible support from health care professionals, there are contrasting stories from participants about the process of obtaining a diagnosis. For some participants, the time from the beginning of symptoms to diagnosis was short due to detection and diagnosis either by their GP or in an emergency department. One participant was diagnosed by chance as they experienced an episode of AF whilst at hospital for an appointment for an unrelated condition. A common route was for the participant's GP to advise a visit to A&E where the AF was diagnosed and treatment commenced.

Two participants reported that the delay in getting an appointment with a cardiologist led to an anxious wait. "*I thought I was going to die there and then….. I felt I hadn't got long to live*" (P115)

Other participants however reported that they found it difficult to have their symptoms taken seriously and to gain a diagnosis. Of note are the two participants whose symptoms had been disregarded by health care professionals who subsequently saw a newspaper article for attending a pulse check as part of Heart Rhythm Week[7]. They went along and had their pulse checked and were diagnosed this way and set on a course of appropriate treatment.

One of these participants had been told by their GP that their symptoms were due to stress of caring for a sick relative and as their symptoms got worse, felt a dilemma.

> "*I knew that it clearly wasn't right and I didn't know what to do because I had been told that it wasn't anything to worry about*" (P104)

This has parallels with the other participant diagnosed at the pulse check who had been sent home from hospital after an emergency admission and told there was nothing wrong even though they were still experiencing a "racing pulse" (P106). He described how this felt

> "*I felt confused, cheated, I thought you know there is something wrong, why are they telling me there is nothing wrong? How do I go about sorting*

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[7] Heart Rhythm week aims to raise awareness and promote better understanding of heart rhythm disorders and is coordinated by Arrhythmia Alliance (an umbrella organisation for arrhythmia charities)

this out? There's nothing I can do, they just discharged me. ..., I came home, during the week I went to see my GP and he felt my pulse and he said oh there's definitely a missing beat over here. But nothing to worry about said the doctor, my doctor... you do have a little bit of a problem around there but nothing to worry about.... So this was what I kept being told by the professionals" (P106)

The transient nature of PAF seems to have been the reason for a delay in diagnosis for some participants. One participant whose symptoms had begun as "*a strange pulse and fluctuation in my rhythm*" (P112) but had increased until he needed to call an ambulance on several occasions described how this felt

"I had like a 48-hour tape, a 24-hour tape and because it was quite sporadic it hadn't recorded it and I mean to an extent I thought well maybe it's me, but I knew it wasn't. But I did kind of feel a little bit like she was looking at me a bit sceptically. But I guess with no documented evidence you can understand why that would be the case. So in the end I had to force the issue and I said okay, well, give me a tape and I'll go and make it happen. So they gave me a 24-hour (tape) and I went home and I cut the grass and then made it happen and I had to go and lay down. And then I got up and I ran downstairs and made it happen again and I had to lay down and then I brought the tape back and said there you go. She passed it straight on to the registrar and her words to me were what she saw was unsustainable and I was in and had the operation within maybe 10 days." (P112)

When asked how this felt, he replied

"Oh a 100% different. I mean, for a start I felt kind of vindicated because all of a sudden they were taking it really seriously, but that wasn't my main priority, I didn't want to feel vindicated, it was like I wanted to get it done"

This episode is mirrored by that of another participant who reported one episode when their heartbeat didn't return to normal straightaway after vigorous exercise with

the next problem being a transient ischaemic attack[8] (TIA) a year later with an associated hospital admission.

"they did loads and loads of different tests and all the time I was saying well, my heart has been misbehaving on occasions, it's sometimes not beating quite right. But every time they tried it, it was fine. …. I was being discharged from the chest clinic and the doctor … she put my TIA down…she said no, she didn't think it was a TIA, she said I think you've had a bout of migraine. I said I've never had migraine before, and she said well, you know, that's all we can say. And I said but you know, I really feel as though there's something wrong with my heart." (P114)

On this occasion, the participant persisted and was eventually referred to the cardiac clinic

"I saw the doctor and they did an ECG and everything again and he called me in and he said, I can tell you exactly what's been going on and I can make sense of all the history of what's happened in the past year and he diagnosed atrial fibrillation. He said it's not all the time, it's intermittent and we just caught it and, you know, I was so relieved to know what it was and he said you did have a TIA because apparently they're linked, those are the sorts of things that occur." (P114)

Both participants had to push for their symptoms to be taken seriously, a fact that is highlighted as important by another participant. Despite increasingly disabling symptoms and several emergency hospital admissions, she highlighted the importance of being believed even when the irregular rhythm couldn't be caught on an ECG machine.

"She (the arrhythmia nurse) didn't disbelieve me. … every time I popped in for an ECG, that's why I came back as they were trying to catch it and every time I laid down on that bed it stopped. ..she didn't disbelieve that I was telling her it was jumping about all over the place. ….Just having

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[8]Transient Ischaemic Attack (TIA): The symptoms of a TIA are very similar to those of a stroke, but they only last for a short time, sometimes only a few minutes or hours. The person always recovers completely within 24 hours (if not it is a stroke). TIAs are sometimes called 'mini strokes'. (Stroke Association, no date)

somebody who thinks well actually I'm not going mad after all 'cos somebody does believe that you are not very well." (P103)

One of the participants who had struggled to get a diagnosis highlighted its importance:

"you can live with things if you know what the cause is, if they can identify the reason, why this series of occurrences. And it was the not knowing or the fact that possibly, yeah, I wasn't believed, but I knew and so that was very comforting. I can remember distinctly, he called me in and he said I can tell you the reasons why this has been occurring in the last two years of your life. He made sense of it for me" (P114)

Another participant described the emotional impact of a lack of diagnosis and its impact on normal activities:

"I had to force myself in the work situation and it was very hard and I felt very lonely as well because I didn't tell anybody because I didn't know what it was." (P115)

The lack of diagnosis appeared to add to the anxiety and worry participants as they sought an explanation for their symptoms. It is interesting to note that severity of symptoms experienced by these participants did not appear to be linked with speed of diagnosis. The experience of these participants who had to push for a diagnosis or those who had to seek a diagnosis through an alternative mechanism contrast clearly with those whose route to diagnosis was more straightforward. It is therefore apparent that the provision of tangible support to secure a diagnosis is not routinely forthcoming for people with AF.

6.4   Living with AF

Once people had received a diagnosis, they then detailed how they coped with AF and any concerns they had. This seemed to focus on managing ongoing symptoms and treatment including medication and interventions. Participants described varying types and amounts of professional support provided by their health care professionals.

6.4.1 Ongoing symptoms

When participants described the symptoms of AF, there were common themes of exertion; "*it was as if I had been running up hundreds of stairs and was still running up them*" 101 and "*it raced away like a steam train*" (P114). One lady gave a detailed description of the feeling "*It's a terrible feeling It's like having a chest full of gerbils… and they feel as if they are all running around in there*"(P103). Even if participants didn't report feeling their pulse beating rapidly, they reported symptoms such as fatigue, tiredness and shortness of breath.

Some participants also reported how nocturnal symptoms were very disconcerting, with one described it as the "*loneliness of the night*" (P114) and one saying "*as soon as I get into bed I'm listening to my heart*" (P109). One participant described being unable to sleep unless he lies on his left hand side when it "*is impossible, really disturbing*" (P105)

Several participants discussed how they managed when they had an acute episode of AF; most had developed a system of waiting to see if the AF will stop of its own accord and then only going to A&E if the symptoms were worse than usual or if they continued beyond 48 hours. The feeling of symptoms returning to normal spontaneously was described as "*a great feeling of elation*" (P105)

The majority of participants in the study had PAF but one participant with permanent AF described their symptoms

> "*I still get tired and there is still a bit of breathlessness but I pace myself…. So my pulse is quite irregular which is no problem, I haven't had any palpitations which I had had*" (P104).

The only participant with persistent AF reported regularly checking his pulse to see that he was still in sinus rhythm but this may be associated with the fact that he had only experienced the symptom of tiredness before being diagnosed " *it was when I was doing the ECG that I discovered to my amazement that I had AF*" (P102) .

6.4.2 Triggers for AF

Participants with PAF frequently discussed potential triggers for their AF. Some were easily able to identify things that brought on an episode of AF: "*mental stress would bring it on just as much as physical stress*" (P108); "*after a game of squash, my*

heartbeart… raced away like a stream train" (P114); slumping at the computer and cold and flu tablets containing caffeine. However, generally these triggers only accounted for some of their episodes of AF and participants generally reported no consistent triggers for their AF. The one exception was the participant who reported how their symptoms only ever came on at when relaxing or resting, not when being active (P109).

However, most participants reported changing habits to try and prevent the onset of an episode of AF. These ranged from reducing consumption of coffee and alcohol, stopping working out with weights, stopping smoking and managing stress levels "*I won't allow myself to get worked up over it*" (P108). This process appeared to be one that participants went through by themselves with little input or support from health care professionals.

From the perspective of participants, tangible support in the form of effective treatment played an important part in the management of symptoms, whether this was medically management or via an intervention such as ablation or cardioversion. People who were on medication to control their symptoms reported the relief of no longer experiencing symptoms although highlighted if for any reason they missed a dose, the symptoms reappeared so they knew their arrhythmia was still there. Although participants appreciated the control of symptoms "*they seem to be doing their job*" (P109), some participants highlighted the fact that they were not keen to continue taking medicines indefinitely. One participant didn't like the feeling of being dependent on the drugs and attributed his lack of "*va-va-voom*" to the numerous pills he was taking to control his arrhythmia (P112). Amiodarone appeared to be a drug that people particularly disliked; one participant saying vehemently "*I hated amiodarone*" because of the side effects and another described the horrible nightmares and interrupted sleep patterns it caused.

Anticoagulation therapy also caused concern for some participants. One described it as "*devil and deep blue sea, I could have a stroke if I didn't and I could have a bleed if I did*" (P111) and another said he was "*very apprehensive*" to get his levels right so he could have a cardioversion (P102). One participant reported problems with

control of INR[9] due to interaction with other medication and so was telephoned at night and told to go straight to A&E "*which is always frightening*"(P107).

When interventions resulted in a return to normal rhythm, participants reported feelings of relief, "*I woke up and I knew my heart was in rhythm and it was beating normally, it was very emotional*" (P114). This was a direct contrast with those whose intervention had not been successful where one participant described it as a "*huge disappointment*" (P112) and another said "*I felt a little bit despondent… I thought it would work and it didn't*" (P101). Despite the initial apparent success of some interventions, some participants reported a recurrence of their symptoms and were keen to have repeat procedures in an attempt to reduce symptoms, describing the decision as a "*pretty easy decision*" (P112).

From the descriptions of participants, the provision of tangible support in the form of medical treatment was more consistently available than the provision of tangible support when participants were trying to obtain a diagnosis from their symptoms.

6.4.3 Spirituality and religion

Spirituality and religion also featured in the accounts of living with AF. Two participants found that religion provided them with a mechanism to help when they had an episode of AF:

"because I'm RC I took my rosary out and I thought let's divert my attention, so I said a rosary and I was halfway through the second …. It calmed me down" (P106)

"being able to get up at night, walk around, sit down, read the Bible, pray, very comforting and recognising that one day in the future I will die and when God says time is up, time is up" (P114)

In addition, spirituality was a theme that was mentioned spontaneously by some participants.

"it made me think about the reality of the end of life" (P101)

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[9] INR International Normalised Ratio: The INR is a way of measuring how fast the blood clots (NHS Choices, 2013)

"you have to face your own mortality…. And I've not had to do that before" (P114)

6.4.4 Information

All participants identified informational support as important and essential. Whilst some were satisfied with the informational support they received from their health professionals, others felt they were not given adequate information in a timely manner and others reported conflicting information which they found extremely confusing.

Many participants reported using the internet to supplement information given by their health professionals, implying an inadequacy in informational support. However, internet content would often leave the participant with even more unanswered questions: "*I have just been looking for an explanation really of the conditions….I have found several – it's a bit confusing*" (P105). "*Going onto the internet and searching 'atrial fibrillation' I found some stuff which I would rather have not discovered"* (P111)

This is reinforced by one participant who spoke of how they no longer chose to use the internet as an information source: "*I haven't googled for a long, long time, maybe years because it just doesn't do any good. You sit there and just read different people's experiences*" (P110). Therefore, the use of the internet to provide surrogate informational support in lieu of adequate support from their health care professionals did not appear to address their informational support needs.

Being able to contact health professionals by phone or email for information, especially if their symptoms had changed, was identified by participants as extremely useful. People with PAF were especially keen to know what they should do if they had an acute episode of AF when at home. Participants who had not had such access to informational support highlighted it as a gap in their care.

Participants wanted information on a range of subjects including medication and its effects, anticoagulation therapy, diet, physical activity and exercise as well as the risks associated with AF. Risk was a key issue for two participants in particular. One younger participant who appeared confident in managing their condition introduced the concept of risk very early in the interview;

"It's been a bit of a worry really because I haven't really been clear about what the risks are while the heart is in that pattern….It's never really been made clear to me" (P105)

This lack of clarity regarding risk contrasted with the account of another participant who had a health care background:

"I don't think I ever came across a patient with atrial fibrillation who had had a stroke, it was just a complication I knew could happen, so depending how you see risk it's either a rare complication from if you're sitting over there, but if you're the patient with the atrial fibrillation perception of risk increases so you think oh my God, you know. And I think because stroke is such a devastating complication, even if the risk is small, you can't put it to the back of your mind" (P111)

In summary, participants gave detailed accounts of their experiences of the treatment they received for AF. Their reports were overall positive indicating satisfactory tangible support, although some participants would have preferred not to be dependent on their medication. However, their testimonies indicated that they were less satisfied with the informational support provided.

6.5 Emotional impact of AF

All participants conveyed the emotional impact of AF, expressing a range of emotions from frustration about the impact of their condition on their life, through to anxiety, apprehension and fear. Participants reported that uncertainty at the diagnostic stage and also throughout the course of their condition meant that they wanted support from their health care professionals to negotiate what one person described as the "*emotional rollercoaster*" of AF (P114). They also felt apprehensive about the future and reported struggling to maintain a positive outlook.

Additionally, patients experienced a range of emotions during the course of treatment: uncertainty as to whether the treatment would work, happiness when interventions were successful and despondency when they were unsuccessful

"We've got the right one at last, we've got the right one" and that felt a feeling of great relief" (P101)

"My heart is beating in rhythm again and it just felt so good. It really, really was an amazingly emotional experience"' (P114)

People whose symptoms limited their activity often reported feeling bored and useless:

"I lay on the couch hoping it wouldn't happen because it was so awful. I turned down work because I am freelance" (P112)

"I didn't have any energy, any fight left. …. I missed a whole year of my life." (P103)

Participants with PAF reported emotional distress due to the unpredictability of their condition:

It's a very disconcerting feeling to know that something bad can happen to you within a matter of seconds. To live with that takes some doing". (P106)

Participants were also concerned that their condition may cause them to damage their heart or have a stroke. *"anxiety that my heart would just suddenly stop" .*

"(I'm) active, healthy and suddenly my ticker is not behaving itself and this could be terminal". (P114)

The uncertainty of their condition clearly had an emotional impact on participants who felt that reassurance from health professionals was important to address this but appropriate emotional support was not always forthcoming.

"nobody has been able to reassure me or address my worries or do anything" (P111)

6.6   Attitude of others

Participants' emotions were also affected by the attitudes of others to their condition. They felt upset by the attitude of others who did not appreciate the nature of their condition and accused them of "putting it on" and "attention seeking".

"The only thing that does upset me from a point of view of emotion if you like is people when they meet me or listen to me say "oh well you look so

*well" or "you sound so well there's nothing wrong with you really" and I have been accused of putting it on and you know taking advantage of it and I'm **not** I mean, people don't, I mean if they saw my file they would probably believe that yes something has really happened. But a lot of them are thinking I'm making a mountain out of a molehill and this upsets me because I can't help my external appearances and the fact that the medicine is doing its job in controlling everything but if I stop taking the medicine, it would all go back to what it was so I'm sure the medicine is what keeps me in regularity with the heart beat and all that" (P101)*

Some participants chose not to share their condition with their family and friends due to the fact that their family members were sick or would struggle to cope and they didn't want to be a "burden" (P108). Another reason for not sharing details was due to how they thought their family would react.

"I don't want them nursing me or thinking that I can't cut the mustard any more" (P106)

Participants who did share their condition with their friends and family reported differences in how their relative reacted:

"I think credit has to be given that they haven't been alarmist". (P110)

"they've been extremely unhelpful as they are worried – so they've been worse than me and I've had to calm them down" (P104)

Participants reported difficulty explaining their limitations due to a lack of understanding about their condition. People were asked why they couldn't walk faster or do certain aspects of their job:

"there's certainly an ignorance about atrial fibrillation and what effects it does have".(P111)

The lack of external signs was a common theme raised by participants. One person reported that people had said "*you don't look ill at all*" (P101) and felt as if people thought they were feigning an illness. One participant reinforced this when praising their understanding spouse

"I'm sure a lot of people wouldn't be as understanding and I suppose because you're sitting there, you've got no outward symptoms, it's not like your leg's broken or you're bleeding or something like that". (P112)

One participant reported the reaction of friends once they were told of his condition *"They were rather taken aback because it had never even entered their mind, they just thought I was unfit or something" (P111)*

One participant reported differing reactions from different people with whom he discussed his condition, one of whom *"pulled a face and said that's nasty".* This contrasted with another friend who said *"don't worry about it, I've had it and it's just something I can live with"* (P105)

The reassurance of being able to discuss their condition with someone else who had AF was identified by several participants, even where the symptoms and treatment were different.

"we were soul mates and that was very reassuring. To be able to talk to someone else who had exactly the same thing" (P114)

Overall, the emotional impact of AF affected participants in a range of ways including uncertainty, anger, anxiety and frustration. In addition, they reported the emotional distress caused by the attitudes of friends, family and colleagues. Despite all participants articulating the emotional impact of AF, there were very few occasions when participants detailed having received emotional support from the health care professionals involved in their care.

6.7   Activities of daily living, physical activity and exercise

The impact of AF on activities of daily living, physical activity and exercise featured in all accounts of their experience of living with AF. Participants reported how their habits, hobbies and work were all affecting by their condition. Gardening, vacuuming and shopping were all activities that were reduced or curtailed. One participant was particularly upset at not being unable to cook the traditional family Christmas dinner. Two respondents reporting not taking job opportunities that meant travelling out of the country as they were concerned about what might happen whilst they were away and several people expressed concern about what their colleagues thought

"I don't know how they put up with me at work cos half the time I was away with the fairies last year" (P103)

Some participants reported a reduction in activity levels due to the effect of their symptoms, whilst for others they felt it was important to take things easy to avoid worsening their condition.

"I try not to overdo it … just in case, I don't know whether I would bring it back" (P102)

"I'm concerned about doing it…. I just don't know what the consequences would be. …It might trigger it off" (P106)

Despite the impact of AF on activities of daily living, physical activity and exercise, the majority of participants received little help, support and information regarding physical activity and exercise from health professionals, including those who underwent interventions to treat their AF. The exception to this was one previously very active participant who was keen to resume previous activities and who was offered an exercise treadmill test after their first intervention.

"I thought right, this is my opportunity, everyone is here if I collapse or if my heart stops or something goes wrong, I know I'm going to get good medical care. So I took it to the limit….but nothing misbehaved so that was very reassuring, very reassuring. And I returned to my normal active routine" (P114)

In this incidence, the provision of tangible support also provided emotional support and reassurance. Therefore, the lack of tangible and informational support for the majority of participants was also likely to result in an associated need for emotional support.

Both participants in permanent AF reported limitations to the amount of activity they could undertake, with both describing it as a somewhat unusual feeling:

"It's a physical limitation. It's very odd, because it's not breathlessness and it is not a feeling of tachycardia that slows me up, it's something else… it seems to come from my legs, not my heart and lungs" (P111)

"I know that I have to stop…. it is a strange tired, it is very strange to explain but you just can't do anything" (P104)

However, only one participant with permanent AF reported that their health professional had discussed this issue with them and provided them with tangible support in the form of coping strategies to understand their limitations. Professional support appears to be lacking with regard to physical activity and exercise for this group of patients with AF.

6.7.1 Fear Avoidance Beliefs

The first two interview participants both spontaneously raised the issue of physical activity during their interviews, leading to specific questions being included in subsequent interviews. The first participant reported how he had changed his activity as a result of his AF symptoms and the second described how he slowed down and changed their activities whilst waiting for an intervention to restore their rhythm as he was "very apprehensive" (P102). This had a consequential impact on his physical activity levels after treatment:

"I don't know whether I would bring it (the AF) back but I don't have the same strength that I had before" (P102).

Five participants specifically stated that they felt physical activity brought on an episode of their irregular heartbeat. This had the associated effect of them believing that they should not do physical activities in case it brought on an episode of their irregular heartbeat. One participant specifically stated that they avoided running when they were in AF as they didn't think it was appropriate to increase the heart rate further. However, the participant who had an exercise treadmill test after their intervention was reassured that it was safe to exercise and it would not make their irregular heartbeat worse. This was the only example of professional support that addressed these beliefs regarding physical activity.

In contrast, two participants explicitly stated that physical activity did not cause their AF:

"I've been relaxing or resting when it started every time. You know it's never ever gone funny when I've been active" (P109)

"I've been sitting quietly most of the time, I haven't been very active so it can't be activity that sets this off" (P106)

However, despite this both these participants reported that they felt they should be doing more physical activity than they were currently doing. One attributed this to arthritis of the knees and the other because *"I'm an inherently lazy person"* (p106), suggesting that both could have benefited from professional support to increase their levels of activity.

The picture regarding the activities that people could not do as it might make their irregular heartbeat worse was less straightforward. Nine participants reported that they had reduced their levels of physical activity due to their AF. However this appeared to be due to the effect of the symptoms as opposed to a belief that they could not do these activities. These participants reported that once their symptoms were controlled either through medication or by interventions, they were able to do more than previously possible. However, both participants with permanent AF described it as a physical limitation that prevented them from doing more.

"I've come to realise it is a physical limitation. It's very odd it's not breathlessness and it is not a feeling of tachycardia that slows me up… It seems to come from my legs not from my heart and lungs…. It's just a feeling that I shouldn't push them any further, that I am close to the limit of my exercise capacity" (P111).

The use of the FABQpa questions revealed that some but not all participants did believe that physical activity brought on an episode of their irregular beat. This appeared to be linked to participants believing that they *should* not do physical activity as it might make their irregular heartbeat worse. There was limited professional support to dispel these beliefs. The picture regarding participants' beliefs that they *could* not do physical activities as this may make their irregular heart beat worse was less clear given the impact of symptoms on functional and exercise ability. Tangible professional support in the form of competent medical care to control symptoms was therefore clearly important to ensure that people had positive beliefs about their ability to carry out physical activity.

6.7.2 Physical activity

Several participants reported how their activity levels had decreased since they had AF and how they had changed the type or duration of activity due to the effect of their AF. These changes were made independently of any professional support. One participant explained how they had dealt with the impact of their symptoms on their activity levels without support from professionals.

> *"If I try and walk a long distance I get out of breath and I get tired…I had an opportunity to acquire this (electric) chair so I'm going to use it… It means I can go anywhere I like now and I'm totally independent" (P108)*

Given the health benefits of physical activity, the lack of professional support in this area could have a detrimental effect on the overall health of people with AF. This is demonstrated by the comments of one participant:

> *"I've put on loads of weight in this three year period, mostly because I haven't done anything, I don't have any kind of vavavoom anymore…. I want to …exercise and try to get back to where I was" (P112)*

Participants with PAF also reported fatigue and an overall impact on activity and fitness levels:

> *"I was very tired, very fatigued and feeling less and less fit. Now I'm not the fittest person in the world but … I was on a cycle where the less fit I'd get, the less exercise I was talking and so the less fit, it was a vicious cycle" (P110)*

Professional informational support explaining the benefits of physical activity and the need for exercise for wider health gains was not evident in the accounts given by participants. This lack of informational support could explain the perception that physical activity could cause problems for people with PAF. One participant reported that when in AF, "*I would avoid running as I don't really think it is appropriate to increase the heart rate whilst it is doing that*" (P105), whilst for other participants there appeared to be direct links between physical activity and episodes of AF: "*I think we overdid it on that occasion, I think that's why it happened*" (P107)

One participant reported explicitly how they were able to bring on an episode through physical activity:

So they gave me a 24-hour (tape) and I went home and I cut the grass and then made it happen and I had to go and lay down. And then I got up and I ran downstairs and made it happen again and I had to lay down and then I brought the tape back and said there you go" (P112)

There was a contrast between the accounts of participants; one reported their heartbeat not returning to normal after a game of squash whilst another reported "*my attacks haven't happened while I've been strenuous*" (P109)

Although influencing participants in differing ways, it is clear therefore that symptoms of AF still played a significant part in the lives of participants by affecting their activities of daily living and shaping their physical activity behaviour and choice of activities. Professional support in this field appeared to be minimal, despite the health benefits that an active lifestyle can provide and therefore this is a gap in support that should be addressed.

6.8   Support from health professionals

Participants were specifically asked to identify the most and least helpful support they received from health care professionals (HCPs) using the questions that have been used in previous work in the field of social support (Dakof and Taylor 1990; Martin et al 1994; Masters et al 2007). The professionals identified are shown in Figure 5 and Figure 6 overleaf.

Figure 5: Health care professional providing most helpful support
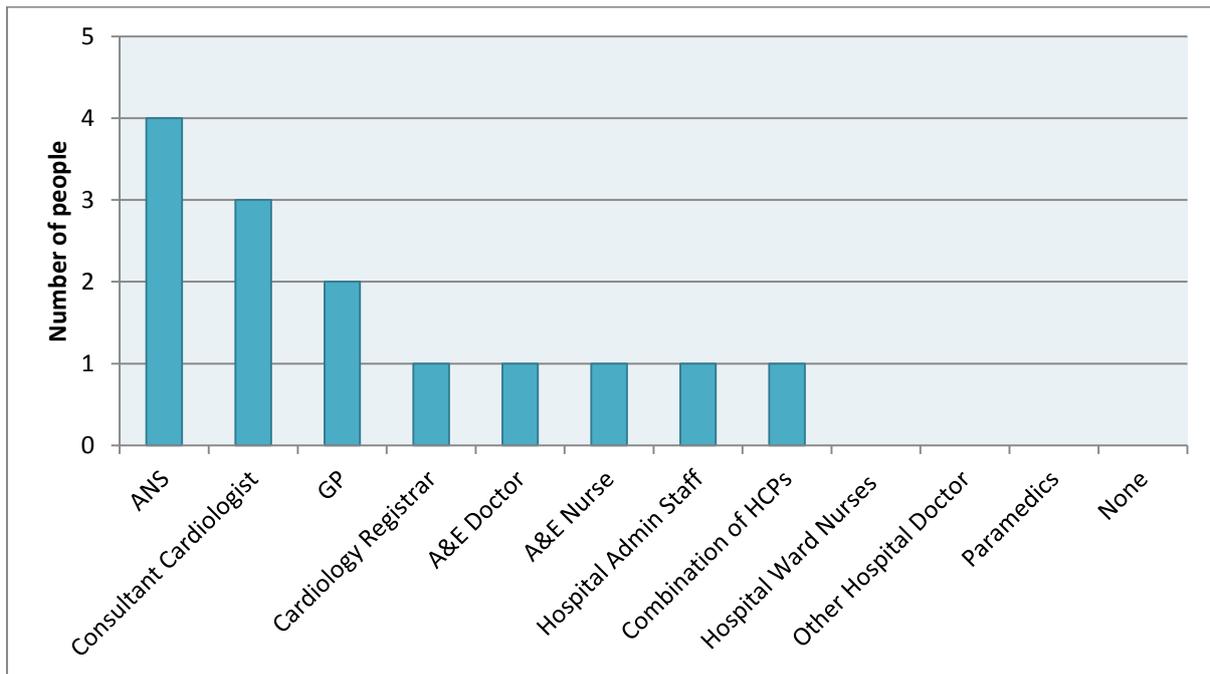
Arrhythmia nurse specialists provided most participants with helpful support, with consultant cardiologists and GPs also frequently providing helpful support.

Figure 6: Health care professional providing least helpful support
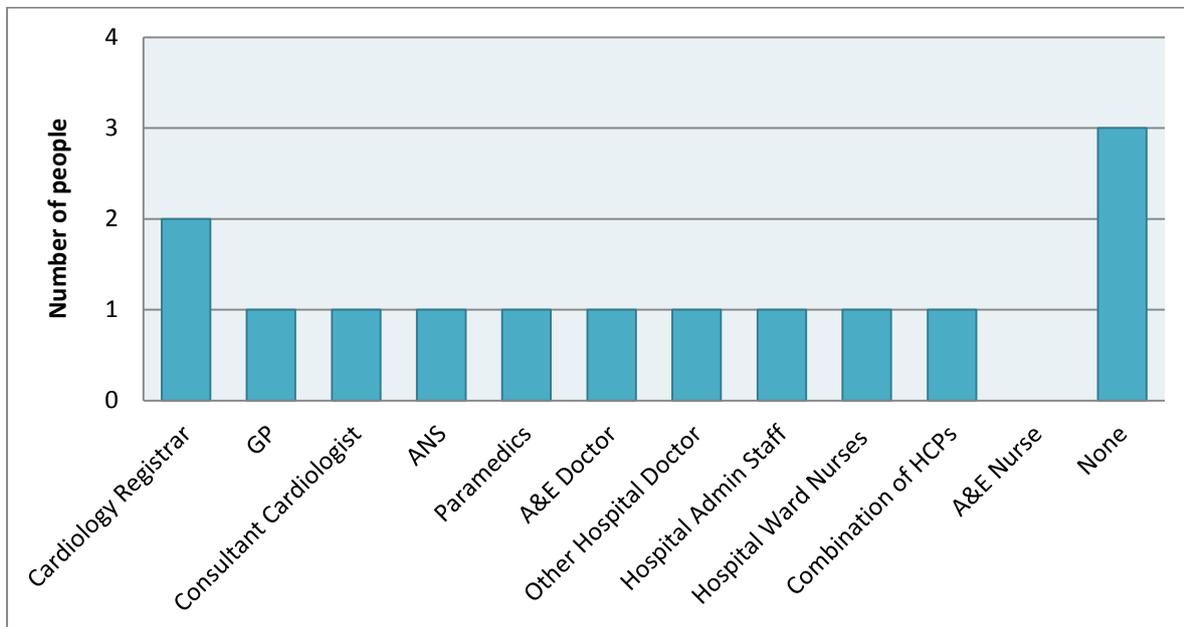
Three participants reported that they had received no unhelpful support from the professionals involved in their care. Although least helpful support was spread across all health care professionals, cardiology registrars appear to provide least helpful support more frequently.

Examples of the most and least helpful support provided by participants were coded to the three categories of professional support using the approach of other authors described previously (Dakof and Taylor 1990; Martin et al 1994; Masters et al 2007) Details of the specific most helpful and least helpful behaviours are shown in Table 10 below:

Table 10: Most helpful and least helpful behaviours by support category

	Most helpful	Least Helpful
Tangible support	- Called an ambulance when acutely unwell - Organising tests - Prescribing correct drugs - Being there when I need support - Clear answer about anticoagulation - Ability to contact doctor and nurse specialists - Person to contact	- Problems with catheter after procedure - Diagnosing AF as stress (incomplete examination) - Having ECG in ambulance in cold - Nurses too busy to look after you - Left on a trolley in A&E with no cardiac monitor
Emotional support	- Reassurance HCP was coordinating care - They trust in what you are telling them (ie, believing in you) - Reassuring - Gives confidence - Making you feel you're going to be OK (when in A&E) - Treating it normally	- Not believing I was ill - Loss of confidence in nurse who didn't listen - Not appreciating how worried I was about the stroke vs bleeding dilemma - Doctor who didn't believe me
Informational support	- Explaining things - Clear explanation	- Lack of information about appointment dates - Inconsistency of information

There were differences in the frequency in which categories of professional support were reported as most helpful and least helpful and this is shown in Table 11 below.

Table 11: Categories of Support Provided by Professionals

n=14	Emotional	Informational	Tangible	Nothing
Most helpful support	7	0	7	0
Least helpful support	4	2	6	2

Equal numbers of participants reported emotional support or tangible support as the most helpful support provided but no participants reported informational support as the most helpful support they received.

The most unhelpful support was spread across all categories; however reports indicated that a large number of participants perceived they had received incompetent medical/nursing care. In addition, negative emotional support was also reported frequently.

6.9 Other Supportive Behaviours

Additionally, during the interviews, participants spontaneously mentioned areas where they felt they had received good support from health professionals involved in their care, including ongoing reassurance, high quality of care and drawing of diagrams to explain the workings of the heart. However, participants also highlighted gaps in support during their accounts of which informational support was the most prevalent.

> *"OK, I have been diagnosed with AF, how do I live with it, what do I do, all these things" (P102)*

> *"I don't know how to help myself with this fibrillation" (P106)*

Although some participants wanted information to be able to manage their condition themselves, one participant specifically described wanting health professionals to direct their care.

"He knew exactly what to do and how to answer my questions…I just felt in a rather old fashioned way he was taking the paternalistic role which is what I wanted of him" (P111)

6.10 Summary

The interviews have provided comprehensive accounts of patients' experiences of living with atrial fibrillation, offering a detailed description of the issues and challenges participants have encountered and the varying levels of tangible, informational and emotional support provided by health care professionals at all stages of their journey.

The accounts demonstrate inconsistency in the process of obtaining a diagnosis including the emotional impact of having to convince health care professionals of the severity of their symptoms. Tangible professional support in the form of a diagnosis was extremely important for participants.

Patients experienced a range of emotions during the course of treatment: happiness when interventions were successful and despondency when they were unsuccessful. Patients reported that uncertainty at the diagnostic stage and also throughout the course of their condition meant that they wanted support to negotiate the "emotional rollercoaster" of AF. However, not all patients received such support from their health professionals. Being able to contact health professionals (by phone or email) to ask for information or if symptoms changed was highlighted as a helpful support mechanism. Some identified it as a gap in provision.

Some participants reported a loss of confidence in their health professionals if their treatment was not well managed or if there were inconsistencies or a lack of clarity regarding treatment options. Participants who were looked after by AF specialists felt it was reassuring to be treated by someone who had obvious experience of managing the condition. Emotional support in a timely fashion was highlighted as imperative but despite this, such professional support was not always provided.

Patients wanted information on a range of subjects: medication and its effects, diet, physical activity and exercise. Many participants reported using the internet to supplement information they were given by their health professionals. However, this often left the patient with even more unanswered questions, highlighting the

importance of effective informational support from health care professionals. The interviews also uncovered a significant unmet need for informational support on the risk of AF.

This chapter has detailed how it is clear from the interviews that participants had differing professional support needs and that these were not always met by their health care professionals. These accounts also identify gaps in provision of such support and indicate how the participants' experiences of AF could have been improved through improved professional support. The following chapters will provide an overview of how the qualitative phase links to the quantitative phase, will describe how the findings from the interviews have informed the development of the study questionnaire and will detail the quantitative phase of the study.

7 Linking the Qualitative and Quantitative Phases of the Study

Having completed the qualitative phase of the study, it is essential to consider how this links with the quantitative phase to form a mixed methods study that is more than the sum of the component parts. Fundamental tenets of pragmatic mixed methods research have been stated to be that the mixed methods study should be more than the component phases of the study and that there should be a clear rationale for conducting the mixed methods study (Heyvaert et al 2013). These areas are explored in more detail in section 0 (10.1.1 Quality specific to mixed methods research). However, it is important to detail the linkage between the qualitative and quantitative phase to understand how these phases combine to achieve the research aims and objectives.

Given the lack of available evidence regarding the lived experience of patients with AF and the paucity of published studies exploring professional support, it was important to gain an understanding from the perspective of the patient as to their experience of living with AF and to identify the types of support that would be required from healthcare professionals, This information was generated through the qualitative interviews and then used to inform the development of the quantitative questionnaire. Creswell and Plano Clark (2007) describe such a process of using findings from qualitative data to inform instrument design, describing how the data analysis reveals quotes, codes and themes that can play a role in the design of an instrument. During coding, specific points were identified as components of tangible, emotional and informational support and these were used to develop the key items for the questionnaire.

This study has therefore used integration through building, taking the results from the interview phase to inform the development of the quantitative questionnaire and the collection of data in the subsequent phase. Although validated items from other scales and instruments were used where possible, there was no tool available to measure professional support. Therefore items were generated from the codes and categories identified at the qualitative phase. Table 12 (page 116) and Appendix D provide more detail of how quotes from the interview were converted into corresponding survey items and more detail on the other items included in the questionnaire is available in section 8.4 (Questionnaire development).

Chapter 10 (Quality) provides more detail on the integration between phases in mixed methods studies and how this has been achieved in this study.

8 Methods – Subsequent Quantitative Phase

The overarching aim of this study was to identify and examine the professional support needs of patients with AF. The purpose of the exploratory sequential design was to explore the views of participants with the intention to use this information to develop an instrument to establish the professional support needs of this group of patients. This chapter details the methods used in the quantitative phase and how the questionnaire was developed from the findings of the interviews.

8.1 Questionnaire administration

Following the difficulties in recruiting participants to the interview stage, it was necessary to consider possible options for administrating the questionnaire. The time constraints of doctoral study combined with the "gatekeeping" of medical staff experienced during the qualitative phase meant that it would not be feasible to guarantee an acceptable response rate within the time frame required using hospital outpatient clinics and so alternative approaches were considered. The Atrial Fibrillation Association (AFA) is an international charity which focuses on raising awareness of AF by providing information and support materials for patients and medical professionals involved in detecting, diagnosing and managing AF and has over thirty affiliated groups worldwide. Its aims are to:

1. To provide support and information on AF to those affected by this condition

2. To advance the education of the medical profession and the general public on the subject of AF

3. To promote research into the management of AF

Through previous contact, the AFA were aware of the research study and had expressed enthusiasm to help and support the research and a willingness to invite their members to participate in the research if relevant. The AFA provides support to its members through a range of mechanisms: a helpline, a comprehensive website, an online forum and monthly e-bulletins with quarterly hard copy newsletters. In partnership with the AFA, it was agreed that the mechanism for recruiting

questionnaire respondents for this study was through the AFA e-bulletin, using an online survey tool, Surveymonkey[10].

8.2   Sample population

Although using AFA members would be a different population of people with AF to the qualitative phase, it was clear that this would still add to the limited body of knowledge regarding the professional support needs of people with AF. The issue of using different groups for different phases of the study will be addressed under data quality in the 10.1.5 Legitimation section.

With regard to the proposed population for the quantitative phase, it is important to consider issues affecting the membership and make up of support groups and organisations. Regarding membership of support groups, initial work looks at traditional support groups with regular meetings. In Krizek et al's (1999) study of breast cancer women and prostate cancer men, they found that men were less likely to join support groups, whilst Cella and Yellen (1993, abstract) report that in cancer support groups, "*there is an under-representation of people of color, men, and the poor among group participants*". Levy's (1976) work on support groups in general suggested that they are predominately used by white, middle class to upper middle class women and disproportionately underutilised by male, minority and individuals of low socioeconomic status. Taylor et al (1986) summarise research relating how the use of support groups is related to support received from other sources. They report that individuals may join support groups because other sources of social support are inadequate for meeting their psychosocial needs. In addition, people may join support groups if they have unsatisfying relationships with medical caregivers, although they also report that there is data to indicate that some patients are encouraged to join support groups by their physicians.

Looking at the use of the internet for health related support, Bjornsdottir (1999) reports that health information seekers are more likely to be older and of female gender than the general internet user population. However, Cotton and Gupta (2004) investigated the characteristics of online and offline health information seekers and reported that the mean age of the internet health information seeking group was

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[10] Survey Monkey is web-based survey software. For more information see
http://www.surveymonkey.com

eleven years younger than that of the non-internet health information seeking group. However they highlight that as older adults are one of the groups shown to be increasing their internet usage, "*future researchers may find the strong age differences reported in this study have declined over time*" (Cotton and Gupta (2004, p.1803). An American national survey (Wagner et al 2004) investigating use of the internet for health information by the chronically ill found that in those individuals with heart problems only, 33.8% of individuals reported using the internet for information or advice about health or health care. However, the percentage of individuals with heart disease using the internet for health information in the study is likely to be higher given there was also a category of people with two or more conditions using the internet and the known associations between heart disease and some of the other conditions under investigation in this study (eg. hypertension and diabetes). Focusing specifically at online support groups, Agnew (2001, p.iii) states that users of online support groups are "*usually white, affluent, well-educated, and computer-savvy*". However, it is often difficult to accurately assess the demographics of online users due to the use of pseudonyms (Bjornsdottir 1999).

The literature appears to indicate that although traditionally membership of support groups may have been middle aged, middle class women, the use of online groups may not reflect this, especially with the changing demographics of internet users. However, the internet appears to provide a useful support mechanism for people with chronic illness summarised by the work of Tetzlaff (1997, p.298) looking at consumer informatics in chronic illness:

> "*The literature and ongoing experience with on-line systems point to the potential power of computer support to address a number of important needs of the chronically ill. Consumers appear positive disposed toward on-line solutions*".

Eysenbach and Wyatt (2002) highlight that due to self selection, there is a non-representative nature of respondents to Internet surveys, which is described by Taylor (2000) and Eysenbach and Wyatt (2002) as the volunteer effect. Best et al (2001, p. 134) emphasise that "*no support exists for the assumption that a representative sample of Internet users can be drawn*" and it was recognised that this online approach for the quantitative phase could have issues of selection bias.

Although recruitment of participants through the AFA's e-bulletin would exclude people without access to the Internet, in 2013 in Great Britain, over 83% of the population had access to the internet (Office for National Statistics, 2013). This fact combined with the literature showing that online health support was accepted by a range of demographic groups would minimise the impact of selection bias. The AFA (personal communication, 2010) indicated that approximately 3,500 of a total of 7,000 AFA members had stated electronic communication to be their preferred mechanism for correspondence and that the demographics of these 3,500 were not obviously different from the overall membership. Therefore no particular group would be excluded by this recruitment strategy even though it is obviously a subset of their members.

Therefore, in line with the pragmatic approach to the overall study, it was decided that the use of an online survey in partnership with a well-known organisation through an already established communication mechanism would provide an indication of the professional support needs of people with AF, something that is currently lacking in the literature. The issues of legitimation, data quality and potential bias will be discussed in more depth in the Quality chapter which addresses quality across both elements of the study.

8.3   Sampling

A potential approach to sampling could have been to randomly select people from the AFA membership and email them an invitation to participate in the online survey. However, as this would have increased demands on the AFA who would have needed to carry out the randomisation to protect member confidentiality, a volunteer sampling approach was adopted. Considering Best et al's (2001) view that it is not possible to get a representative study of internet users, the quantitative phase would therefore be a non-probability study aiming to identify professional support needs of people with AF in light of very little evidence in this field. This volunteer approach to recruitment would mirror that of the qualitative phase and was felt to be an acceptable approach to recruitment.

Various authors have highlighted that online surveys are much less likely to achieve response rates as high as paper surveys (Nulty 2008, Bech and Kristensen 2009). Balter et al (2005) reported that differential access to the internet has restricted the

use of web-based methods to studies in specific groups with internet access such as university students, employees at certain companies or known internet users, giving even less reliable information to provide an indication of possible response rates for this health related study recruited from an charity membership.

Given volunteer sampling was adopted as the sampling strategy for this phase of the study, there was little reliable indication of anticipated response rate and therefore it was difficult to carry out formal sample size and power calculations. It was anticipated that there would be an adequate response rate from the 3,500 AFA members who were emailed the invitation to provide an indication of the professional support needs of people with AF. A follow up invitation to participate was planned and a back-up strategy of sending paper copies of the questionnaire was considered in case required.

8.4   Questionnaire development

The content of the questionnaire was based mainly on information from the findings of the qualitative interviews. Creswell and Plano Clark (2007) describe the process of using findings from qualitative data to inform instrument design, describing how the data analysis reveals quotes, codes and themes that can play a role in the design of an instrument. Having identified the items for inclusion in the questionnaire, they describe how researchers should "*consider the inclusion of validated items from other scales or instruments*" (Creswell and Plano Clark, 2007, p.124) and this approach was therefore adopted during the questionnaire development.

Key quotes and themes from the qualitative interviews were used to identify areas for inclusion in the quantitative questionnaire. Table 12 gives an example of how the qualitative data was used to build items for inclusion in the survey. The full table can be viewed in Appendix D: How qualitative data informed quantitative questionnaire.

Table 12: Example of how the qualitative data was used to build items for inclusion in the survey

Quotations from the qualitative phase	Corresponding survey item
Informational Support	
I don't know how to help myself with this fibrillation (P106)	Managing AF at home
I'm still not clear after four episodes of this and after a lot of research on the internet and having seen a lot of health professionals I still don't know what to do when it happens (P105) *The nurse was quite angry, she said your doctor should never have sent you up here like this, you should have got an ambulance and gone straight into A&E (p109)*	What to do when get irregular beat
It's been a bit of a worry really because I haven't really been clear about what the risks are while the heart is in that pattern….It's never really been made clear to me (P105)	Risks of irregular heart beat
I think being on the drugs is quite a large factor of it. When I was in my prime I was taking about 40 odd pills a week something like that and there's a financial implication there. … If I'd known ..that that could be the timescale, I would have certainly gone out and got this NHS pre-pay thing (p112) *The other thing is that there is a psychological effect to feeling like you're dependent upon a bunch of drugs (p112)*	Medicines
For example I know my INR was going high a bit and I thought I didn't want it to go too high so I started bleeding so I altered my diet a bit get a bit more veg, more greens so my INR come down a bit today (P102)	Diet and food

The following sections will detail the specific items chosen for inclusion in the questionnaire and where appropriate, provide background information relating to scales or instruments used in the process.

8.4.1 Advice from experts and informants

Onmuegbuzie et al (2010) suggest that local experts can play an important role in ensuring instrument fidelity by providing an emic perspective. Therefore, the themes identified from the initial qualitative phase were checked for face validity and content validity with clinical experts in the field and the patient panel[11] as part of seeking advice regarding general areas for inclusion to ensure the questionnaire had strong instrument fidelity. There were no apparent issues.

The patient panel suggested that an important factor in the need for professional support would be the length of time that a person had been diagnosed with atrial fibrillation. They felt that people who had had AF for longer had developed their own ways of coping and it was the newly diagnosed people who needed more support from professionals. Therefore duration of AF was included in the questionnaire to see if this hypothesis was true. The panel also felt that the frequency of symptoms would be an important factor based on the assumption that the more often a person experienced symptoms, the more support they would require. Frequency of symptoms was therefore included in the questionnaire.

Professionals involved in the care of patients with AF had frequently expressed the fact that they felt that paroxysmal AF was harder for patients to manage due to its transitory effect and the fact that there was often no sign to indicate imminent onset. Therefore, in order to identify those patients with PAF, classification of atrial fibrillation was included as a question. Respondents were asked to describe their patterns of AF with the medical classifications alongside each option to minimise unknown as a response.

The study's clinical advisor also suggested that treatment strategy could influence the need for professional support. Rhythm control indicates that active attempts are being made to get the person back into sinus rhythm but rate control means that there is an acceptance of the abnormal rhythm and therefore it was suggested that this could impact on support needs. Medication usage was proposed as a surrogate for treatment strategy as by asking respondents to identify the drugs they were taking, it would be possible to allocate them to rhythm or rate control using the author's clinical expertise in this field.

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[11] For more information on the patient panel, see the section on Public and Patient Involvement (page 63)

8.4.2 Measuring Symptoms

Given the range of symptoms and their impact described during the interviews, this was an important area for inclusion in the questionnaire as increased symptoms could be linked to an increased need for support from professionals. The symptoms described by participants in the qualitative phase appeared to be comprehensive (based on the researcher's clinical expertise in this field) and so were used to develop a list for questionnaire respondents to select which symptoms they had personally experienced.

During a consensus conference, Kirchhof et al (2007) identified that symptoms were the most common reason for patients with AF to seek medical attention but that despite this, there was a lack of a practicable instrument to assess AF-related symptoms. The conference therefore proposed the European Heart Rhythm Association (EHRA) AF symptoms classification scale as an appropriate mechanism to measure symptoms even whilst acknowledging that this scale is yet to be validated (Kirchhof et al 2007). Despite any apparent subsequent validation following the consensus conference, in 2010 the European Society of Cardiology guidelines on AF stated: "*Clinical evaluation should include determination of the EHRA score (of AF related symptoms)*" (Camm et al, 2010, p. 2378). Therefore it was felt appropriate to include this tool to assess symptom severity as this would be in line with other work in the AF community and the scale is shown in Table 13 below.

Table 13: EHRA Score of AF-related Symptoms

Classification of AF-related symptoms (EHRA score)	
EHRA Class	**Explanation**
EHRA I	'No symptoms'
EHRA II	'Mild symptoms'; normal daily activity not affected
EHRA III	'Severe symptoms'; normal daily activity affected
EHRA IV	'Disabling symptoms'; normal daily activity discontinued

Taken from Camm et al (2010 p.2378)

As the patient panel (described in detail at page 66) had indicated that people experiencing symptoms more frequently might need more support, it was important to select a method to describe frequency. As well as symptom severity, Kirchof et al (2007) also identified that frequency of symptoms could be classified into three groups, namely occasionally (less than once per month), intermediate (once per

month—almost daily), and frequent (at least daily). At the ethics committee meeting for the quantitative phase, it was suggested there should be a further category for those people with silent AF who did not experience symptoms and this was therefore added to the questionnaire.

8.4.3 Health care professionals

During the interviews, the researcher had been able to elaborate on, explain and probe the term 'healthcare professionals' but this would not be possible in the questionnaire. Therefore in order to ensure that people understood the term "healthcare professionals" and considered the full range of professionals involved in their care, a list of health professionals was included early in the questionnaire for people to select those who they had seen. This list was expanded after the pilot phase and an option was also included to allow respondents to add extra professionals not already listed.

8.4.4 Normal Activities

Interview participants highlighted how having AF had changed their approach to a range of activities. These themes were therefore used to develop specific questions using a five point Likert scale, from completely disagree to completely agree, looking at the effect of AF on normal activities relating to hobbies, travel and type and amount of physical activity to establish whether this was a field where people with AF could benefit from increased support from their health care professionals. After the pilot stage of the questionnaire development, an additional statement was added to highlight the fact that activities may have changed due to factors other than AF as this was identified as an issue by one of the pilot respondents which could otherwise have influenced findings.

8.4.5 Physical activity

Physical activity arose as a key theme for participants in the initial qualitative phase. Therefore there was a need to find an appropriate tool to include in the questionnaire to find out more about activity levels of people with AF and to see if this was an area where people with AF could benefit from increased professional support. The World Health Organisation (2012) highlight the fact that despite the significant role of physical activity in public health, there is a "*lack of consensus*" as to which instrument should be used to measure levels of physical activity in populations. Timperio and Salmon (2003) state the measurement of physical activity can range

from a simple approach (three questions in a survey) to a complex approach (assessing individual levels of physical activity energy expenditure). Given this questionnaire was measuring a range of topics including physical activity, the physical activity instrument needed to have a smaller rather than larger number of items to avoid overburdening participants with a lengthy questionnaire. Additionally due to the online administration, the physical activity instrument also had to be suitable for self-completion by participants.

Therefore, the General Practice Physical Activity Questionnaire (GPPAQ) was selected as this had been developed to "provide a simple 4-level Physical Activity Index (PAI) reflecting an individual's current physical activity" (Department of Health 2009, p.18). The GPPAQ is reported to have good face validity, good construct validity and is repeatable (Department of Health 2009) and is recommended at Government level (NICE, 2011a) as a validated tool to assess activity levels in primary care. It was therefore felt to be an appropriate tool to measure physical activity in this study. Responses from participants would be used to calculate their PAI as detailed in the questionnaire guidance (Department of Health 2009).

8.4.6 Fear Avoidance Belief Questionnaire

During the first two interviews, participants mentioned the fact that they had changed their levels of physical activity as a result of their AF. Questions were then added to the interview schedule based on the work by Waddell et al (1993) looking at fear avoidance beliefs. The Fear-Avoidance Beliefs Questionnaire (FABQ) (Waddell et al 1993) was developed to assess fear-avoidance beliefs in patients with chronic low back pain. The FABQ is a 16-item self-report questionnaire aimed at quantifying the beliefs of how work and physical activity affect pain and whether they should be avoided. Williamson (2006) reports that the reliability and validity of the FABQ has been established by a range of studies and it is acceptable for use in clinical practice. There are two subscales, fear-avoidance beliefs for work (FABQwork) and fear-avoidance beliefs for physical activity (FABQpa). There are scored on a Likert scale of 0–6, from 'strongly disagree' to 'strongly agree', with higher sum scores indicating stronger fear avoidance beliefs. Williamson (2006) comments that the psychometric properties of the subscales are better established than the total FABQ so the use of the subscales may be preferable.

During the interviews, questions from the FABQpa were adapted for people with AF to test whether they were appropriate for people with AF. The questions were well received and understood by interview participants and indicated that there was a range of fear avoidance beliefs present which may be influencing physical activity levels of people with AF. Responses indicated that there would be benefit in further investigation of the fear avoidance beliefs of people with AF as this may provide information for health care professionals as to which people might need more support. Therefore the modified FABQpa statements were included in the questionnaire as shown in Table 14.

Table 14: Statements for FAB used in questionnaire

FAB Statements for people with AF
I believe that my irregular heart beat was/is caused by physical activity
I believe that physical activity brings on an episode of my irregular heart beat (either at the time or immediately afterwards)
I believe that physical activity might harm my heart
I believe that I should not do physical activities which (might) make my irregular heart beat worse
I believe that I cannot do physical activities as these (might) make my irregular heart beat worse

8.4.7 Emotional, Informational and Practical Support

Using the key issues identified in the interviews (see Findings from Qualitative Interviews from page 85), statements were designed for each of the elements of professional support. The statements were grouped in sections relating to each of the elements of support. Respondents were asked to select their level of need for support from one of four categories: no need, low need, medium need and high need. These levels were chosen as the interviews indicated that need was a sliding scale rather than a dichotomy.

A particular lack of informational and emotional support was identified by interview participants who had been treated with an ablation and so specific questions relating to support post ablation were included using the same structure as for emotional, tangible and informational support. A skip function was added to the online

questionnaire to ensure that only respondents who had undergone an ablation were asked to respond to these questions.

8.4.8 *Most helpful and least helpful healthcare professional*

In order to provide some comparison with the limited available evidence relating to professional support (Dakof and Taylor 1990; Martin et al 1994; Masters et al 2007), questions were included relating to the most supportive and least supportive health care professional. The interview transcripts together with the clinical expertise of the researcher were used to generate a list of healthcare professionals involved in the care of people with AF. Respondents were then asked to select the professional who had been the most supportive and to describe what was the most supportive thing this professional had said or done. Conversely respondents were also asked to select the professional who had been least supportive and the thing that this person had said or done that had made them most angry, annoyed, or upset or had simply rubbed them the wrong way.

8.4.9 *Additional feedback*

In order to ensure that all relevant areas relating to support from health care professionals were addressed, respondents were also given the opportunity to provide any further information through a free text box at the end of the questionnaire.

8.5 Ethical Issues

Ethics approval for the quantitative phase was sought from the University of Hertfordshire (UH) Research Ethics Committee (REC) for Nursing, Midwifery, Social Work, Criminal Justice and Counselling to proceed with a pilot study and a cross sectional survey to support the development of a questionnaire to look at the professional support needs of people with atrial fibrillation with recruitment through the AFA. Approval to proceed with both the pilot and the main questionnaire was granted on the understanding that if there were any changes to the content of the questionnaire following the pilot, these were reviewed by the committee and further approval gained before proceeding with the main questionnaire (See Appendix E: Quantitative Ethics Application).

As with the qualitative phase, the five main general ethical principles highlighted by Silverman (2010) were addressed to in order to protect participants. Table 15 shows how these were addressed in the study.

Table 15: Ethical Principals and how they were addressed in quantitative phase

Ethical Principle	How addressed in study
Voluntary participation and the right to withdraw	The AFA were responsible for sending the newsletter to potential participants who were then able to choose if and when they took part in the study. The first page of the online questionnaire information sheet detailed the study and explained that the participant could chose to take part or to withdraw at any stage.
Protection of research participants	Participants were asked to give their age and sex to support analysis of the findings to see if these variables impact on the support needs of participants. Additional personal data was only required if participants requested an individual summary of the findings from the study. Participants were also informed that study findings would be provided in a future edition of the AFA newsletter so that participants do not have to provide personal details if they did not wish to and they would therefore not be disadvantaged by this decision. Information about the security and non-disclosure of personal or identifying data was given to subjects in the information provided prior to participation in the study. This included information regarding the fact that personal details would not be shared with others and regarding the handling, processing, storage and destruction of information in accordance with the UK Data Protection Act 1998. The SurveyMonkey feature enabling IP address collection of survey participants was turned off when the survey was created. Access to the online survey was password protected and results were stored in an electronic spreadsheet stored on secure NHS computers with password protection. Access to the data was restricted to the Chief Investigator and the database containing personal data was stored in line with the NHS Trust's Information Governance Policy. Personal data was stored in line with Department of Health guidance for retention of medical records and will be

Ethical Principle	How addressed in study
	destroyed in line with Department of Health guidance.
	Although direct quotations from respondents may be published in reporting the findings of this study, these will be anonymised and care will be taken to ensure that identification of individuals is not possible.
Assessment of potential benefits and risks to participants	Potential risks and benefits were assessed and outlined as part of the UH REC application (see Appendix E1: UH Ethics committee application form).
	There was the potential risk that participants might experience some mild mental distress if any of the questions contained in the survey highlighted the impact AF has had on their life. To address this, the questionnaire was set up so that people could choose to either pass on any questions that caused distress or so that they could take a break and come back to the questionnaire.
	The AFA provides information and support for people with AF and so people were able to contact the AFA if completing the questionnaire caused mild mental distress for the participants. In addition, the researcher had a list of contact details for Mindinfoline and local Mind associations to support those people who contacted the researcher directly. No participants reported any distress directly to the researcher.
	The main disadvantage for participants was the time element required to complete the questionnaire. The research design was reviewed by an external patient group who indicated that they felt it was important for healthcare professionals to learn more about the support needs of this group of patients and felt that the time commitment was an acceptable burden to ensure this was achieved.
	The study may not directly benefit participants themselves, however the information from this study will help improve the care of people with an irregular heartbeat, leading to an improved service for patients.
Obtaining informed consent	The first page of the online questionnaire consisted of an information sheet which detailed the purpose of the research, the lead researcher and the organisations involved as well as addressing potential risks and benefits to participation.
	As it is a questionnaire study, completion of the questionnaire was understood to mean that participants were consenting to take part in the study (in line with UH Ethics Committee guidelines 2010-2011). In addition,

Ethical Principle	How addressed in study
	the first question asked participants to choose between two options: "I have read the above information about the research and am happy to take part. By completing the questionnaire, I understand that I am consenting to take part." "I do not wish to take part in the study." The questionnaire was designed so that participants were not able to proceed without selecting one of these options. It was made clear at the beginning of the web based survey that completion of the questionnaire in entirely voluntary and in no way compulsory.
Doing no harm	Maintaining confidentiality of participants is important to ensure no harm. As detailed earlier, identifiable information was removed from responses and care taken to ensure patients could not be identified from direct quotes. This was particularly important as participants were being asked to recount examples where they felt they had received unsupportive care from health care professionals which could have ramifications for their care moving forwards. As described earlier, the questionnaire was set up so that people could choose to either pass on any questions if they caused distress or so that they could take a break and come back to the questionnaire. The AFA provides information and support for people with AF and so people were able to contact the AFA if completing the questionnaire caused mild mental distress for the participants. In addition, the researcher had a list of contact details for Mindinfoline and local Mind associations to support those people who contacted the researcher directly. No participants reported any distress directly to the researcher. The information page of the questionnaire reinforced that respondents could withdraw at any stage.

8.6   Piloting questionnaire

Numerous authors propose piloting of questionnaires before their widespread use (McColl and Thomas 2000; Gorard 2003; Saris and Gollhofer 2007; Creswell 2009 and Onwuegbuzie et al 2010). McColl and Thomas (2000) propose that testing the questionnaire in this way with a small sample of the target audience will ensure it is understandable and acceptable to the target audience and Creswell (2009) suggest

that this helps improve questions, formats and scales. Not only was this important for questions that had been developed directly from the interview findings but also for the testing of established paper instruments that had been converted into the online format of this phase of the study.

In order to identify people with AF who could participate in the pilot questionnaire, the AFA posted a message on their online forum asking for volunteers to take part. From here a small group of fourteen volunteers was recruited to be involved in such a pilot. Pilot participants were emailed to provide information regarding the research and to provide the link to the pilot questionnaire. As well as including an additional question on the pilot to ask for feedback to improve the questionnaire, participants were also invited to send feedback direct to the researcher via email. The aim of the pilot was to assess the questionnaire for feasibility, accessibility, appropriateness and ease of understanding of both the questions and the online survey tool. Participants were asked to complete the questionnaire within a three week timescale.

Following the completion of the pilot questionnaire, changes were made to the questionnaire to reflect feedback. The major amendment was that the questions relating to emotional, tangible and informational support needs were amended to allow respondents to indicate whether or not their needs were met by health care professionals as respondents reported that the questions in the pilot did not allow them to express if they had needs which had not been met. An item worded as "*fear of having a heart attack or stroke*" was separated into two items following feedback regarding the particular fear of stroke associated with AF.

Three additional types of health care professionals were added after they were identified by pilot participants. Questions relating to support after cardioversion and other procedures were removed after pilot participants reported repetition if they had received more than one intervention for their AF, with only the questions relating to ablation left in the questionnaire. Questions relating to support after ablation were kept in the questionnaire as responses indicated this was the procedure after which participants had most need for help. This also matched with accounts from interview participants. In line with the ethics application, the changes to the questionnaire were sent back to the committee for review. Approval to proceed with the main

questionnaire was then granted. (Full details of the changes can be found in Appendix E4:Post pilot amendments to questionnaire.)

8.6.1 Access

AFA members who had requested electronic communication received the e-bulletin containing the invitation to participate in the study, including a link to the web based survey. The e-bulletin was sent to potential participants by the AFA and the principal investigator was not be given access to personal information of potential participants. A copy of the e-bulletin from June 2011 can be found in Appendix F.

The issue of gatekeeping which was identified at the qualitative phase was also relevant during this quantitative phase. The wording and placement of the link to the online survey were chosen by the AFA and it is therefore possible that potential participants did not access the survey as a result.

Participants who chose to participate were directed to a SurveyMonkey web based questionnaire to complete the survey online. Participants were asked to confirm that they consented to take part as the first question of the survey; those who did not select this option were not able to complete the survey. Additionally, people under the age of eighteen were not able to complete the study. It was made clear in the study information that participation in the survey was entirely voluntary and in no way compulsory. A reminder to encourage participation was sent in a subsequent electronic bulletin (see Appendix G)

A contact email address for the researcher was included in the front page of the questionnaire in case people had any questions. Only one person used this email address and this was to update the researcher on progress with their AF since completing the questionnaire.

8.7 Data Collection

Participants entered their responses directly into the online survey tool. At the end of the collection period, the survey was closed to further responses and all data exported to an excel spreadsheet and then into IBM SPSS Statistics v21 (SPSS) for analysis. At this point, data was screened for inaccurate and missing entries and actions taken to adjust where appropriate. Detailed information is provided in the relevant finding sections.

8.8   Data analysis

As described in the data analysis section of the initial qualitative phase (page 81) four of Onwuegbuzie and Teddlie's (2003) seven stages of mixed methods data analysis were incorporated in this study. Data reduction and data display were the focus of the qualitative phase with the major emphasis in this quantitative phase being on data reduction, data display and data comparison. Data integration is reported in the section "Quality specific to mixed methods research" (page 172). Data analysis was performed using SPSS to assess the impact of study variables on variables of interest.

8.8.1 Development of the null hypotheses

The study aimed to explore the differences in professional support needs in relation to five study variables: symptom severity, symptom frequency, classification of AF, treatment strategy and duration of AF. The interviews revealed that there may some relationships between these five study variables and other variables of interest (support, fear avoidance beliefs, physical activity (as in index, change in hobbies and everyday activities, travel avoidance, changing amounts and changing types)

In order to identify whether there were any relationships between these variables as suggested by the interviews but also to examine any relationships that may exist that were not suggested by the interviews, null hypotheses were developed to look at all combinations of "study" and "other" variables. Because the analysis was considering hypotheses beyond those suggested by interviews, non-directional hypotheses were considered in order to allow the data to indicate any direction that exists. Table 16 shows the range of null hypotheses grouped into sections of the questionnaire.

Table 16: Null hypotheses for study

Support (Information, emotional, tangible)
a)   There is no difference in each type of support need across different symptom severity categories
b)   There is no change in each type of support need across different symptom frequencies
c)   There is no difference in each type of support need across different classifications of AF
d)   There is no difference in each type of support need across duration of AF
e)   There is no difference in each type of support need across different AF treatment strategies

Fear Avoidance Beliefs (FABs)
a) There is no difference in FABs across different symptom severity categories
b) There is no difference in FABs across different symptom frequencies
c) There is no difference in FABs across classification of AF
d) There is no difference in FABs across duration of AF
e) There is no difference in FABs across different AF treatment strategies
Physical Activity Index (PAI)
a) There is no difference in PAI across different symptom severity categories
b) There is no difference in PAI across different symptom frequencies
c) There is no difference in PAI across classification of *AF*
d) There is no difference in PAI across different durations of AF
e) There is no difference in PAI across different AF treatment strategies
Changes in Hobbies and Everyday Activities (H&EA)
a) There is no difference in changes in H&EA across different symptom severity categories
b) There is no difference in changes in H&EA across different symptom frequency categories
c) There is no difference in changes in H&EA across different classifications of AF
d) There is no difference in changes in H&EA across different durations of AF
e) There is no difference in changes in H&EA across different AF treatment strategies
Travel Avoidance
a) There is no difference in travel avoidance across different symptom severity categories
b) There is no difference in travel avoidance across different symptom frequency categories
c) There is no difference in travel avoidance across different AF classifications
d) There is no difference in travel avoidance across different AF durations
e) There is no difference in travel avoidance across different AF treatment strategies
Changing Amounts of Physical Activity/ Exercise (PA/E)
a) There is no difference in changing amounts of PA/E across different symptom severity categories
b) There is no difference in changing amounts of PA/E across different symptom frequency categories
c) There is no difference in changing amounts of PA/E across different AF classifications
d) There is no difference in changing amounts of PA/E across different AF durations
e) There is no difference in changing amounts of PA/E across different AF treatment strategies
Changing Types of Physical Activity/Exercise
a) There is no difference in changing types of PA/E across different symptom severity categories
b) There is no difference in changing types of PA/E across different symptom frequency categories
c) There is no difference in changing types of PA/E across different AF classifications
d) There is no difference in changing types PA/E across different AF durations
e) There is no difference in changing types of PA/E across different AF treatment strategies

The initial plan for analysis included the need to assess whether the main study variables had an impact on strength of FAB in participants. In the process of developing and administering the questionnaire and reviewing the literature relating to use of the FABQ in other conditions, the importance of considering the impact of FAB on physical activity, exercise and hobbies was identified as this would show whether FABs were influencing activity behaviour. These tests were therefore added to the plan for analysis as shown in Table 17 below.

Table 17: FAB null hypotheses for study

Fear Avoidance Beliefs
a) There is no difference in changes in H&EA across different FABs
b) There is no difference in travel avoidance across different FABs
c) There is no difference in changing amount of PA/E across different FABs
d) There is no difference in changing types of PA/E across different FABs
e) There is no difference in FABs across different PAIs

The questions relating to those respondents who had an ablation were designed to identify the support needs of this group post procedure, irrespective of classification, symptom severity, frequency, duration or treatment strategy. Therefore, no further analysis was planned for this data and no further need evolved as the study progressed.

For all types of support, to examine relationships between categorical variables, statistical analyses were performed using Fisher's exact test, with the Gamma statistic used to assess the strength of relationship between ordinal variables and Cramer's V test used to measure the strength of association when one of the variables was a nominal variable.

Levels of significance and Strength of relationships
Instead of using the traditional significance level of 5%, due to the fact that multiple tests were being carried out on the data in this study, a significance level of 1% was used for all tests ($p \leq 0.01$). Performing multiple tests made it more likely that there could be a number of small p-values just by chance and therefore using this tighter level of significance would reduce the likelihood of rejecting a null hypothesis which was actually true.

Gamma and Cramer's V

As detailed above, the level of significance for the study was p≤ 0.01 which is therefore the focus of investigation. However it was also felt important to consider those results where the 1% significance was approached but not achieved (p> 0.01 but ≤ 0.05) to ensure that the null hypothesis was not falsely rejected. Therefore the strength of relationship between the variables of interest was considered using either the Gamma statistic (shown by Ɣ) or Cramer's V test. p-values between 1% and 5% will only be considered as important if there is theory or existing research to back up the findings.

The Ɣ statistic was used to assess the strength of the relationship between ordinal variables and Cramer's V test was used to measure the strength of the association when one of the variables was a nominal variable.

Table 18 and Table 19 below show the definitions of the strength of relationship and association used in this study.

Table 18 Strength of relationship between variables and Gamma statistic

Gamma statistic	Relationship between variables
0.00 – 0.24	No relationship
0.25 – 0.49	Weak relationship
0.50 – 0.74	Moderate relationship
0.75 – 1.00	Strong relationship

(Boston University Metropolitan College no date)

Table 19 Level of association between variables and Cramer's V result

Cramer's V	Level of association between variables
>0.5	high association
0.3 to 0.5	moderate association
0.1 to 0.3	low association
0 to 0.1	little if any association

(AcaStat 2012)

8.9   Data Quality and Rigour

As stated in the qualitative methods section, issues of quality for each phase of the study will be considered together with issues of quality for the study overall after both phases of the study have been detailed. Please see the Quality chapter from page 171.

8.10 Summary

This chapter detailed the identification and selection of participants, ethical considerations, data collection and data analysis for the quantitative phase. Findings from the questionnaire are reported in the next chapter.

9 Results of Quantitative Survey

This chapter presents the findings from the self-completion questionnaire.

9.1 Participants

116 completed the initial consent question at the beginning of the questionnaire, with only one person refusing consent. Four people completed only the consent question, leaving 111 people progressing to the eligibility question.

Nine people then chose the option "a family member/friend has AF" with the remaining 102 being over the age of 18 with AF therefore eligible to take part in the questionnaire. Demographics of participants are detailed in Appendix I..

9.1.1 Study Variables

The key variables of interest for the quantitative phase were;

- Classification of AF

- Symptom severity

- Symptom frequency

- Duration of AF and

- Treatment strategy

Although 102 completed the consent and eligibility questions, giving 102 participants, one respondent did not provide an answer regarding classification despite the option "none of the above/not sure/don't know" (n=101) and three respondents did not reply to the questions relating to symptom severity and symptom frequency (n=99).

Duration answers were grouped based on respondents' response to how many years and months since they had first experienced an irregular heartbeat. However, six responses could not be coded due to incomplete/unclear information (n=96)

Table 20: Study Variables

Variable	Frequency	Percentage
Classification (n=101)		
Unknown	5	5.0%
PAF	57	56.4%
persistent AF	10	9.9%
permanent AF	29	28.7%
	101	100.0%
Symptom Severity (EHRA scale) (n=99)		
no symptoms (EHRA I)	7	7.1%
mild symptoms (EHRA II)	40	40.4%
severe symptoms (EHRA III)	45	45.4%
disabling symptoms (EHRA IV)	7	7.1%
	99	100.0%
Symptom frequency (EHRA scale) (n=99)		
Never	5	5.0%
Occasionally	28	28.3%
Intermediate	38	38.4%
Frequent	28	28.3%
	99	100.0%
Duration of AF symptoms (n=96)		
0-2 years	20	20.8%
3-5years	32	33.3%
6-10years	22	22.9%
11-15 years	12	12.5%
16 years +	10	10.4%
	96	100.0%

9.1.2 Treatment Strategy

In order to establish which treatment strategy was being used, respondents were asked to give details of their AF specific medication. This was then analysed to confirm whether a rate or rhythm strategy was being used. Following the pilot survey, in response to feedback from participants, the layout of the questions relating to medication was changed so that respondents selected their medication from a list

of potential options. Therefore for 60 respondents it is not clear whether they are not on any medication or they chose not to answer this question. Therefore, for this approach to be more accurate in defining treatment strategy in future studies, the question layout should give the option of yes/no for each medication choice. However, responses to this study have identified treatment strategy for the remaining 42 respondents as shown in Table 21.

Table 21: Treatment Strategy

Variable	Frequency	Percentage
Treatment strategy (n=42)		
Rhythm	16	38%
Rate	23	55%
Both	3	7%
	42	100%

NB no medication identified for 60 participants as detailed above

The option "Both" indicates where it is not possible from responses to separate out which treatment strategy is being used. Although this approach means that there are a number of respondents for whom it is not possible to identify their treatment strategy, it does provide an indication of treatment strategy which will therefore be used to investigate the research questions.

9.1.3 Symptoms Experienced

Respondents were asked to select which symptoms they experienced with their AF as well as the frequency they experienced these symptoms. Symptom frequency was used as a study variable and is shown in Table 20. Data relating to the types of symptom experienced is useful to describe an overall picture of the experience of people with AF and Figure 7 demonstrates the frequency of reported symptoms.

Figure 7: Self-reported AF symptoms
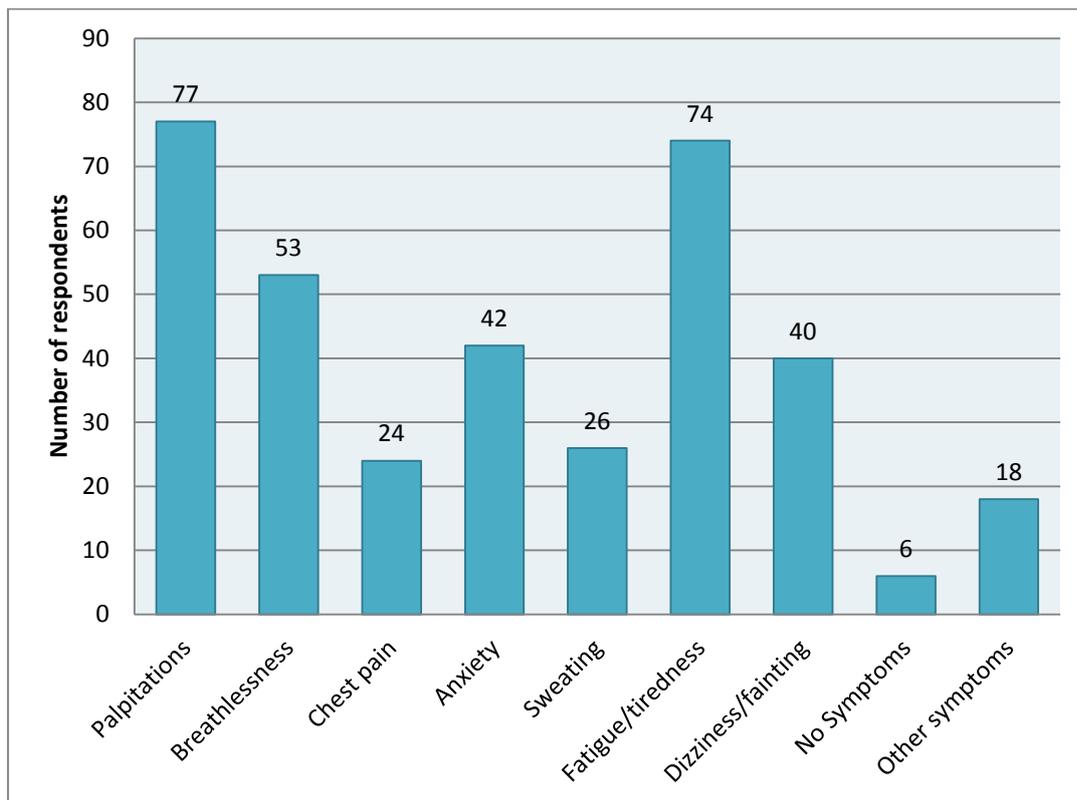
9.2 Levels of need for professional support

For all types of support, to examine relationships between categorical variables, statistical analyses were performed using Fisher's exact test. Analyses were carried out as described in the Data analysis section on page 128 , with the ɣ statistic used to assess the strength of relationship between ordinal variables and Cramer's V test used to measure the strength of association when one of the variables was a nominal variable. Findings are shown in Table 22 to Table 24.

9.2.1 Informational support

Ten types of **informational support** were investigated in the survey. Percentages of respondents reporting no need varied from 9% (risks of AF and what to do if symptoms changed) to 20% (information about how much exercise and what type of exercise). Information about what to do if symptoms change was a particular need with only 9% of respondents reporting they had no need for information compared with 53% of respondents who expressed a high need for information in this area.

Looking at all types of informational support, levels of high need for support ranged from 27% of participants expressing high need for support regarding managing AF at home whereas support regarding what to do if symptoms changed was a high need for 53% of participants.

When considering high need and medium need for support, the majority of participants felt they needed more informational support from their health care professional although there was a range of need across all types of informational support. 62% reported a medium/high need for informational support regarding managing AF at home whereas 80% reported medium/high need regarding what to do if symptoms changed. See Figure 8 for an overview of levels of need for each component of informational support and Table 22 for results of statistical analysis for individual variables and informational support.

Figure 8: Overview of Informational support - different components of support and levels of need
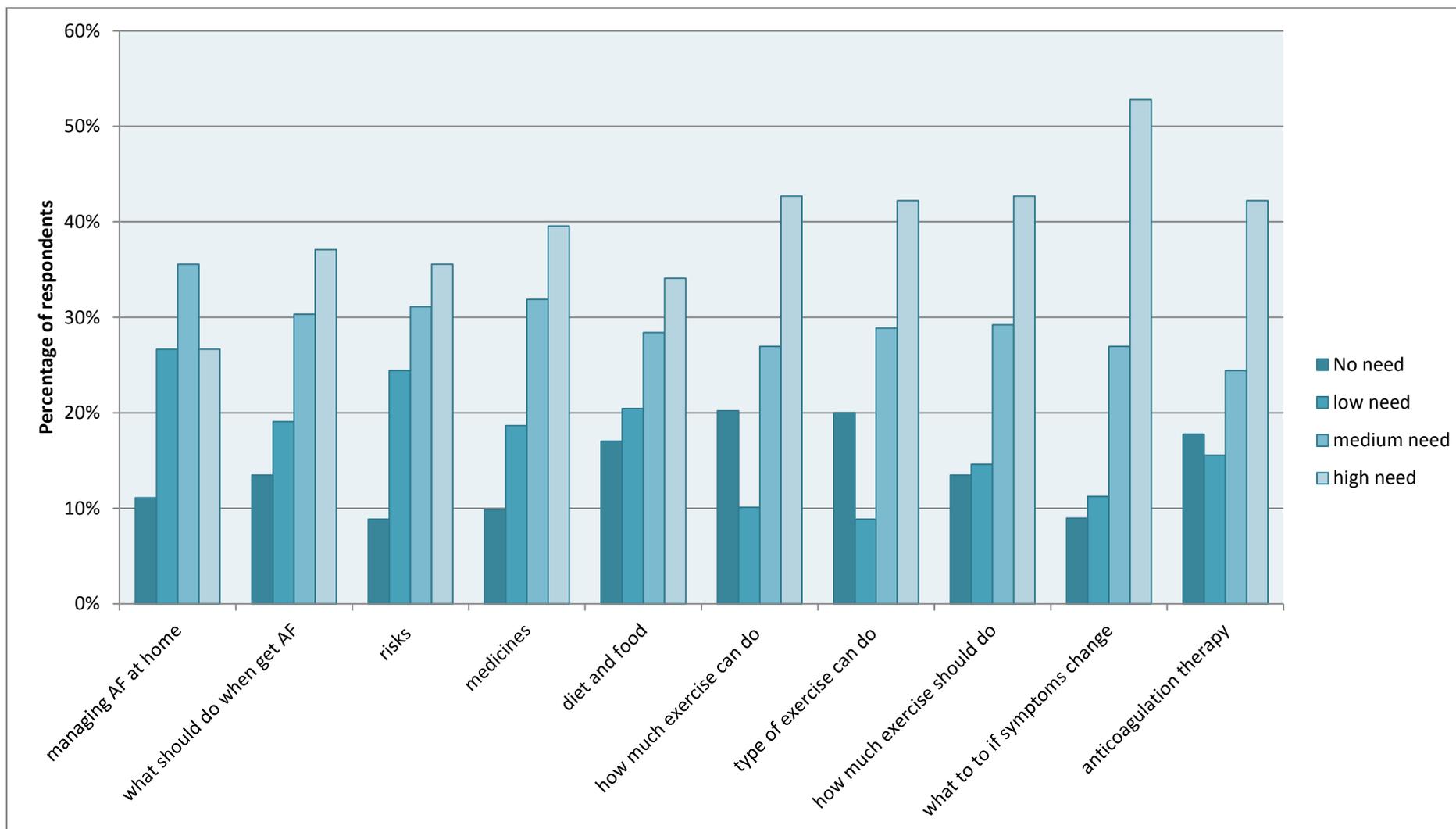
Statistically significant findings

For informational support, there was a statistically significant difference with a moderately strong association between a need for support with managing AF at home for classification of AF (p= 0.003, Cramer's V = 0.281). The study data showed that those people with PAF had a higher level of informational need regarding how to manage their irregular heart beat at home.

Findings indicating an association

As described in the plans for data analysis (section 8.8 page 130), those findings where p> 0.01 but ≤ 0.05 were reviewed to ensure that the null hypothesis was not falsely rejected and therefore the types of informational support where there appeared to be such an association with the study variables were examined. There appeared to be an association between symptom severity and the need for informational support with managing AF at home although this was not significant at the 1% level (p=0.016, ɣ=0.322). The study data indicates that people with more severe symptoms had a higher level of informational need regarding how to manage their irregular heart beat at home and as this would make sense clinically even in the absence of existing evidence, this suggests that there could be a difference between symptom severity and this type of informational support, despite the weak relationship suggested by the ɣ value.

Regarding informational support for what to do if they get an episode of their AF, there appeared to be an association with classification (p=0.05, Cramer's V=0.241). In this study, participants with PAF and persistent AF tended to have medium/high need regarding what they should do if they get an episode of their AF i.e.) those with PAF and persistent AF had a higher level of informational need, suggesting there is an association between the two variables even though Cramer's V indicates a low association. As AF is intermittent in those people with PAF/persistent AF, clinically this would make sense to ensure these patients felt they knew what to do in case of an episode of AF. Additionally findings also indicated that those who have permanent AF have a more even spread of need, which could be due to the fact that their AF is always present, suggesting that there could be an association between these variables despite the low Cramer's V score.

There also appeared to be an association between treatment strategy and informational support regarding what to do if their symptoms change (p=0.034, Cramer's V = 0.386 indicating a moderate association). The study data indicates that participants with rate treatment strategy tended to have medium to high need for informational support regarding what to do if their symptoms change, whereas those with a rhythm treatment strategy tended to have a more even spread of need. Given that rate treatment aims to slow down the rapid arrhythmia, the need for informational support if symptoms change (indicating that treatment has potentially been unsuccessful) suggests that there could be an association between the two variables, despite little existing evidence to support or refute this relationship. There are insufficient numbers of participants in the "both" group to draw any conclusions about this group.

Synopsis – informational support

To summarise, for two particular types of informational support, classification appeared to influence level of need for support. Symptom severity and treatment strategy also appeared to influence need for two other separate types of informational support.

Table 22: Results of Statistical Analysis for Informational Support

	Symptom Severity		Symptom frequency		Classification		Duration		Treatment Strategy	
	p value	Gamma	p value	Gamma	p value	Cramer's V	p value	Gamma	p value	Cramer's V
INFORMATIONAL SUPPORT										
managing AF at home	**0.016**	0.322	0.061	0.269	**0.003**	0.281	0.372	0.100	0.959	0.168
what should do when get AF	0.140	0.374	0.224	0.252	**0.050**	0.241	0.424	0.185	0.854	0.200
risks	0.087	0.278	0.402	0.149	0.055	0.242	0.494	-0.113	0.652	0.232
medicines	0.309	0.117	0.561	0.133	0.932	0.125	0.917	-0.010	0.142	0.313
diet and food	0.640	0.063	0.054	0.323	0.833	0.139	0.145	-0.168	0.877	0.197
how much exercise can do	0.898	0.264	0.785	0.159	0.816	0.147	0.633	0.043	0.972	0.161
type of exercise can do	0.969	0.219	0.265	0.230	0.749	0.153	0.935	0.041	0.973	0.165
how much exercise should do	0.845	0.171	0.789	0.187	0.140	0.227	0.895	0.029	0.673	0.231
what to to if symptoms change	0.949	-0.100	0.889	0.096	0.265	0.199	0.906	0.011	**0.034**	0.386
anticoagulation therapy	0.174	-0.065	0.552	-0.066	0.091	0.247	0.513	-0.037	0.075	0.370

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9.2.2 Tangible support

There were differences in responses depending on the type of tangible support from healthcare professionals. Tangible support relating to help with physical tasks had larger percentages of people expressing no need for support (46% had no need for support about difficulties walking up stairs and/or hills and 64% had no need for support with work around the house).

However, tangible support relating to provision of medical care had less people expressing no need (only 11% had no need for honest explanations about their irregular heart beat and only 11% had no need of support from one health care professional).

15 71% expressed medium or high need for the provision of honest explanations about their irregular heart beat (31% medium need and 40% high need) and 74% expressing medium or high need for support from one health care professional who could talk about all aspects of the condition, treatment and follow up (33% medium need and 41% high need). See Figure 9 for an overview of levels of need for each component of tangible support and Table 23 for results of statistical analysis for individual variables and tangible support.

Figure 9: Overview Tangible Support – different components of tangible support and levels of need
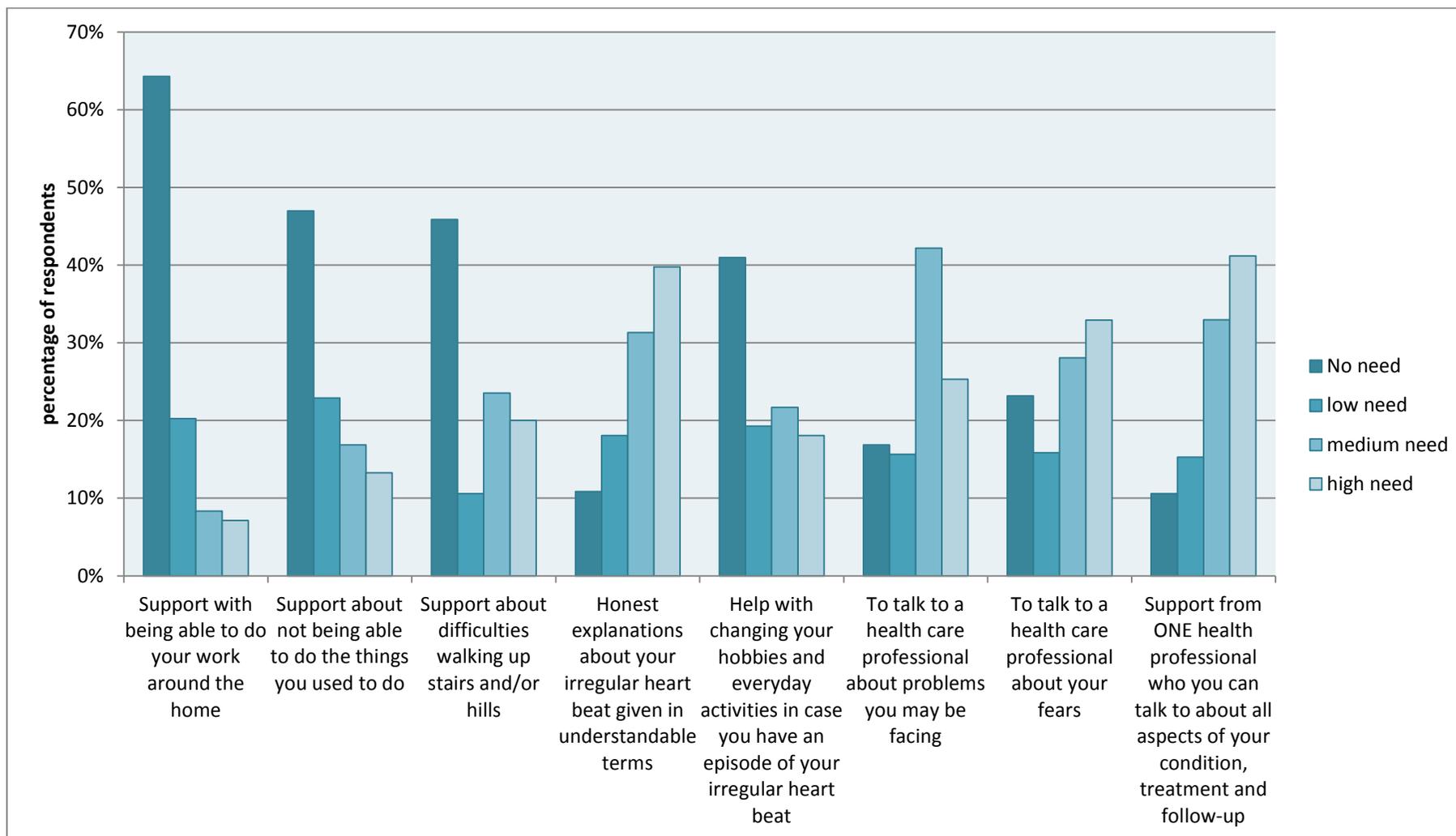
Statistically significant findings

There was a statistically significant difference between EHRA symptom severity and three components of need for **tangible** support. The ɣ statistic indicated a strong relationship for support with being able to do work around the house (p<0.001, ɣ= 0.773) and for support about not being able to do the things you used to do

30 (p<0.001, ɣ=0.837). For support about difficulties walking up stairs and/or hills (p<0.001, ɣ=0.677), the ɣ statistic indicated a moderate relationship. For all three types of tangible support, participants with disabling symptoms (EHRA IV) tended to have medium/high need i.e.) those with most severe symptoms had a higher level of need for tangible support.

Findings indicating an association

The relationship between one element of tangible support and symptom frequency was reviewed as it was approaching levels of significance (p≤0.05 but> 0.01). There appeared to be an association between symptom frequency and tangible support for being able to do work around the home (p=0.045, ɣ=0.620). The study data showed that participants with symptom frequency never/occasional tended to have no need for tangible support with being able to do work around the home, whereas participants with intermediate or frequent symptoms tended to have high need i.e.) those with most frequent symptoms had a higher level of need). Clinically this association would appear logical as more frequent symptoms are more likely to

45 affect a person's ability to carry out tasks. Together with the moderate ɣ statistic, it is reasonable therefore to suggest that there could be a relationship between these two variables.

Synopsis – tangible support

In summary, symptom severity appeared to influence need for three of the eight specific types of tangible support. Symptom frequency also appeared to influence need for one type of tangible support.

Table 23: Results of Statistical Analysis for Tangible Support

	Symptom Severity		Symptom frequency		Classification		Duration		Treatment Strategy	
	p value	Gamma	p value	Gamma	p value	Cramer's V	p value	Gamma	p value	Cramer's V
TANGIBLE SUPPORT										
Support with being able to do your work around the home	**<0.001**	0.773	**0.045**	0.620	0.616	0.170	0.452	-0.053	0.573	0.255
Support about not being able to do the things you used to do	**<0.001**	0.837	0.097	0.494	0.636	0.182	0.757	-0.058	0.920	0.184
Support about difficulties walking up stairs and/or hills	**<0.001**	0.677	0.192	0.404	0.188	0.286	0.664	-0.107	0.966	0.167
Honest explanations about your irregular heart beat given in understandable terms	0.466	0.269	0.077	0.318	0.985	0.128	0.882	-0.094	0.862	0.199
Help with changing your hobbies and everyday activities in case you have an episode of your irregular heart beat	0.091	0.389	0.123	0.360	0.265	0.212	0.962	0.035	0.595	0.257
To talk to a health care professional about problems you may be facing	0.222	0.309	0.813	0.212	0.792	0.162	0.723	-0.121	0.766	0.223
To talk to a health care professional about your fears	0.060	0.344	0.206	0.305	0.291	0.195	0.465	-0.132	0.954	0.176
Support from ONE health professional who you can talk to about all aspects of your condition, treatment and follow-up	0.358	0.358	0.650	0.152	0.782	0.149	0.858	-0.099	0.726	0.228

9.2.3 Emotional support

The need for emotional support from healthcare professionals varied across the 15 types of emotional support studied. Whilst 54% of respondents reported no need for support for feeling bored and/or useless and 46% had no need for support for feeling angry and frustrated, only 10% reported no need for support relating to fear of having a stroke and only 14% identified no need for support regarding fears about their heart condition worsening.

Looking at high need for support, 48% reported high need for support relating to fear of having a stroke, 42% had high need of support regarding fears about their condition worsening and 40% had high need for support about feeling afraid to travel in case they experienced their irregular heartbeat whilst away. Feeling bored and/or useless had the smallest percentage of people reporting high need for support (17%).

Considering medium or high need for emotional support, 75% of respondents needed emotional support from health care professionals regarding fear of having a stroke (27% medium need and 48% high need) and 70% needed emotional support regarding fears about their heart condition worsening (29% medium need and 42% high need). See Figure 10 for an overview of levels of need for each component of emotional support and Table 24 for results of statistical analysis for individual variables and tangible support.

Figure 10: Overview Emotional Support – different components and Levels of need
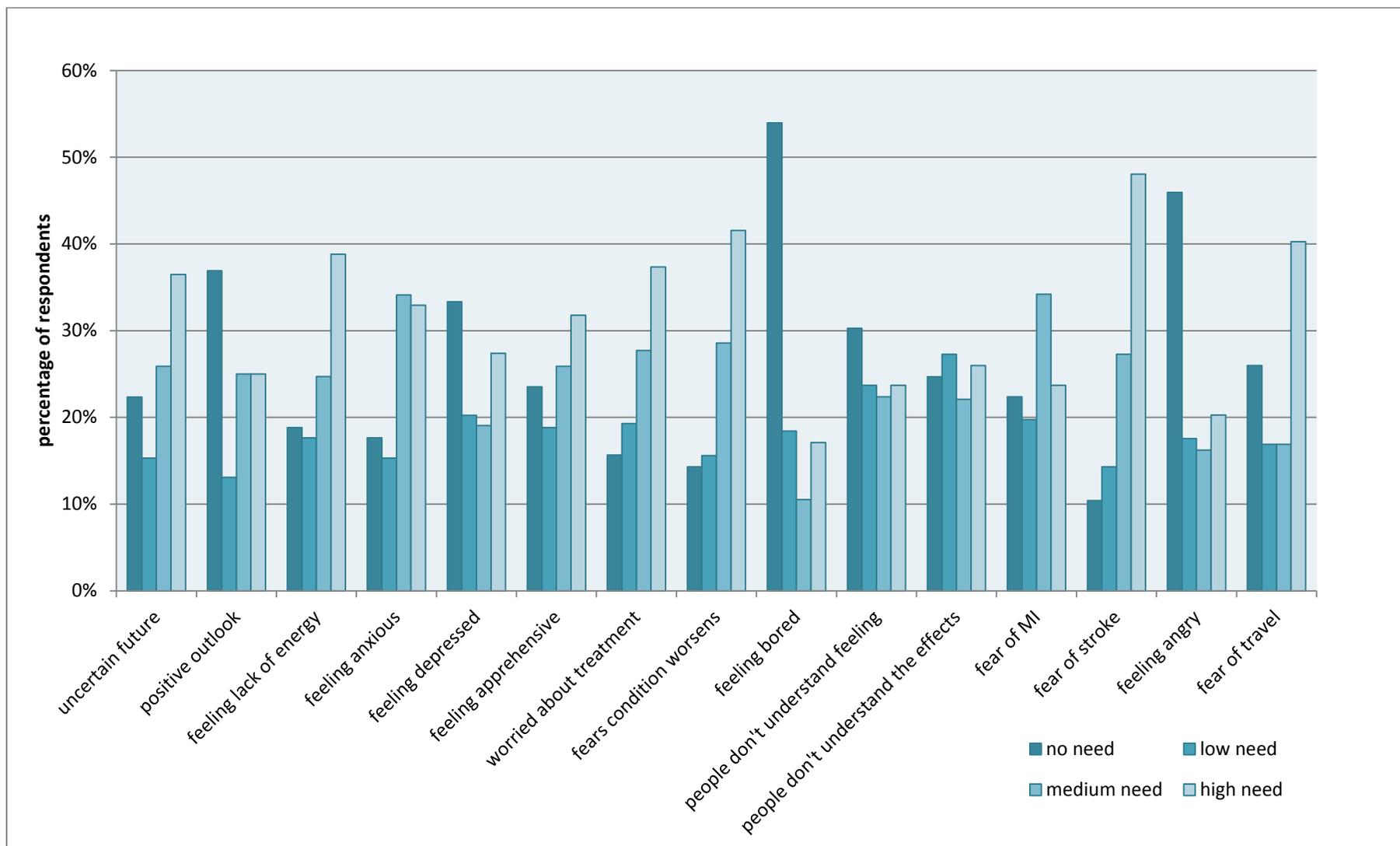
There was a statistically significant difference between EHRA **symptom severity** and six elements of emotional support. The ɣ statistic indicated a moderate relationship for five of these: feeling a lack of energy (p=0.001, ɣ=0.624); feeling bored (p<0.001, ɣ=0.640); feeling that people don't understand how you are feeling (p=0.001, ɣ=0.590); feeling that people don't understand the effects of an irregular heartbeat (p=0.001, ɣ=0.633) and fear of travel (p=0.001, ɣ=0.570). The ɣ statistic indicated a weak relationship for the element of emotional support, feeling depressed (p<0.001, ɣ=0.354). Similar to tangible support, participants in this study with most severe symptoms reported a higher level of need for emotional support.

There was also a statistically significant difference between **symptom frequency** and a need for emotional support with feeling bored (p=0.004, ɣ=0.640). Participants who never/occasionally experience symptoms tended to have no need i.e.) those who experience less symptoms had less need for emotional support about feeling bored and/or useless. This relationship is supported by the ɣ statistic indicating a moderate relationship between these two variables.

Findings indicating an association

Elements of emotional support and their relationship with symptom severity and symptom frequency were reviewed where they were approaching levels of significance (p≤0.05 but> 0.01), as was the relationship between one element of emotional support and treatment strategy.

Considering EHRA **symptom severity** and its relationship with elements of emotional support, the ɣ statistic indicated a weak relationship with both support for keeping a positive outlook (p=0.012, ɣ=0.476) and feeling anxious as a result of their irregular heartbeat (p=0.025, ɣ=0.384).

The study data showed that participants with no/mild symptoms (EHRA Score I/II) tended to have no need for support about keeping a positive outlook whereas participants with severe/disabling symptoms (EHRA III/IV) tended to have medium/high need i.e.) those with most severe symptoms had a higher level of need. Participants with no symptoms (EHRA Score I) tended to have no need for emotional support about feeling anxious as a result of their irregular heartbeat whereas participants with mild/severe/disabling symptoms (EHRA II-IV) tended to have

medium/high need i.e.) those people with symptoms had a higher level of need. Although there is no existing theory to support these findings, the concept of people with the most severe symptoms needing most emotional support would indicate that it is reasonable to suggest there could be a relationship between these variables despite the weak relationship indicated by the ɣ statistic.

There appeared to be an association between symptom severity and emotional support about feeling angry and frustrated (p=0.031, ɣ=0.507). Participants in this study with no/mild symptoms (EHRA Score I/II) tended to have no/low need for emotional support about feeling angry and frustrated whereas participants with disabling symptoms (EHRA score IV) tended to have high need i.e.) those with most severe symptoms had a higher need. As described above, although there is no existing evidence to support these findings, clinically it would seem appropriate to expect those people with the most severe symptoms to need more emotional support, which would indicate that it is reasonable to suggest there could be a relationship between the two variables. This relationship is also supported by the ɣ statistic indicating a moderate relationship between these two variables.

Additionally there were six other elements of emotional support where there appeared to be an association with **symptom frequency** but where this was not significant (p≤0.05 but> 0.01). The ɣ statistic indicated a weak relationship between five of these elements; support in keeping a positive outlook (p=0.019, ɣ=0.475); support about feeling a lack of energy or tiredness (p=0.052, ɣ=0.404); support about feeling apprehensive (p=0.036, ɣ=0.302); support about feeling that people don't understand how they are feeling (p=0.039, ɣ=0.499) and support about feeling that people don't understand the effects of AF (p=0.037, ɣ=0.472).

In the study, participants who never/occasionally experience symptoms tended to have no/low need for the above elements of emotional whereas those whose symptom frequency was intermediate/frequent had medium/high need i.e.) those with more frequent symptoms had more need for these specific elements of emotional support. As with symptom severity, whilst there is no existing literature to support these findings, the concept of people with the most frequent symptoms needing most emotional support would suggest that there could be a relationship between these variables despite the weak relationship indicated by the ɣ statistic.

149

The ɣ statistic indicated that there appeared to be a moderate relationship between symptom frequency and emotional support about feeling angry and frustrated (p=0.030, ɣ=0.550). Study participants with never/occasional/intermediate symptom frequency tended to have no/low need for emotional support about feeling angry and frustrated whereas those with frequent symptoms had medium/high need i.e.) those with frequent symptoms had more need for this type of emotional support. As described in the previous paragraph, whilst there is no existing literature to support these findings, the concept of people with the most frequent symptoms needing most emotional support suggests that it is reasonable to propose there could be a relationship between these two variables.

There also appeared to be a relationship between symptom frequency and emotional support about the fear of stroke (p=0.028, ɣ=0.442). In this study, participants with all categories of symptom frequency tended to have medium/high need i.e.) there is a need for emotional support about the fear of stroke irrespective of symptom frequency. Given the five-fold increased risk of stroke for people with AF (Wolf et al 1991), this is a likely relationship even with the weak relationship indicated by the ɣ statistic.

Similarly, there also appeared to be a relationship between treatment strategy and emotional support about the fear of MI (p=0.041, Cramer's V = 0.456). Study participants with both rate and rhythm treatment strategies tended to have medium/high need i.e.) there is a need for emotional support about the fear of MI irrespective of treatment strategy. Although there is little theory to support this relationship, the concept of a condition affecting the functioning of the heart leading to fear of MI is very conceivable and a moderate association is indicated by the Cramer's V result.   (There are insufficient numbers of participants in the "both" group to draw any conclusions about this group).

Synopsis – emotional support
Summarising the findings regarding emotional support, it appears that classification and duration did not influence the need for emotional support. However, symptom severity appeared to influence nine of the fifteen elements of emotional support, symptom frequency eight of the fifteen and treatment strategy one of the elements of emotional support.

Table 24: Results of Statistical Analysis for Emotional Support

	Symptom Severity		Symptom frequency		Classification		Duration		Treatment Strategy	
	p value	Gamma	p value	Gamma	p value	Cramer's V	p value	Gamma	p value	Cramer's V
EMOTIONAL SUPPORT										
uncertain future	0.078	0.344	0.097	0.381	0.776	0.159	0.920	-0.051	0.686	0.228
positive outlook	**0.012**	0.476	**0.019**	0.475	0.349	0.196	0.351	-0.078	0.765	0.213
feeling lack of energy	**0.001**	0.624	**0.052**	0.404	0.876	0.141	0.507	-0.150	0.118	0.337
feeling anxious	**0.025**	0.384	0.171	0.307	0.349	0.209	0.727	-0.073	0.461	0.267
feeling depressed	**<0.001**	0.354	0.163	0.364	0.155	0.210	0.928	-0.084	0.756	0.226
feeling apprehensive	0.212	0.234	**0.036**	0.302	0.538	0.182	0.906	-0.241	0.873	0.202
worried about treatment	0.078	0.301	0.229	0.198	0.534	0.191	0.847	0.004	0.925	0.196
fears condition worsens	0.438	0.321	0.176	0.367	0.460	0.190	0.134	-0.030	0.087	0.408
feeling bored	**<0.001**	0.640	**0.004**	0.640	0.757	0.164	0.210	-0.179	0.875	0.212
people don't understand feeling	**0.001**	0.590	**0.039**	0.499	0.322	0.205	0.634	0.026	0.556	0.271
people don't understand the effects	**0.001**	0.633	**0.037**	0.472	0.088	0.247	0.830	-0.047	0.156	0.354
fear of MI	0.144	0.266	0.074	0.412	0.634	0.180	0.987	-0.093	**0.041**	0.456
fear of stroke	0.085	0.270	**0.028**	0.442	0.425	0.201	0.929	-0.151	0.093	0.510
feeling angry	**0.031**	0.507	**0.030**	0.550	0.457	0.228	0.066	-0.023	1.000	0.142
fear of travel	**0.001**	0.570	0.061	0.442	0.194	0.229	0.585	0.032	0.618	0.270

9.2.4 Summary – professional support

In summary, symptom severity has most association for need of support across all three types of professional support. Classification and treatment strategy are also associated with a need for informational support and symptom frequency and treatment strategy with a need for emotional support.

9.3 Need met

Participants in the pilot highlighted that they felt it was important to be able to indicate for each type of support whether or not their need had been met by their health care professional and therefore this was included in the main questionnaire. However this is not essential to the main research question and so summary tables are included in the appendix in order to share the information gathered from these questions as this could be a topic for future research beyond the scope of this project. (See Appendix H: Summary tables of needs met for types of support for more details)

9.4 Levels of physical activity

Using Department of Health (2009) guidance, answers to the GPPAQ were analysed and respondents classified into one of four physical activity categories: inactive, moderately inactive, moderately active, active. Questionnaire documentation did not include guidance relating to missing values but respondents who did not complete any section of the GPPAQ were excluded (n=37). However, if there were incomplete responses to individual elements of the GPPAQ (such as cycling), missing values were taken to be 0 assuming that they did not participate in this specific type of exercise/activity (this applied to 14 people). This approach was used as people had completed other sections of the GPPAQ so it was assumed that they had left it blank as not applying to them. For future online studies, it is therefore suggested that the key elements of GPPAQ should be set up to require an answer to ensure a complete set of data. This however was not possible in this study due to conditions set by the ethics committee approving the study

Figure 11: Activity Levels calculated from GPPAQ
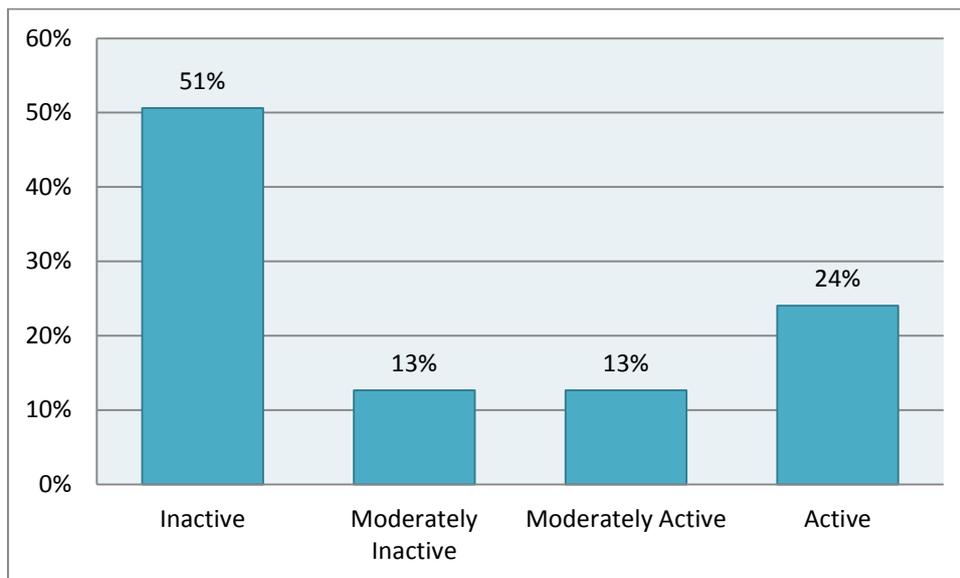
Respondents classified as inactive, moderately inactive and moderately active are not meeting the Chief Medical Officer's physical activity recommendations (Department of Health 2012); in this study this equated to 75.9% of respondents.

9.5   Fear Avoidance Beliefs

Figure 12 shows frequency distribution of sum scores (0–24) for the Fear-Avoidance Beliefs Questionnaire, physical activity subscale (FABQ-pa) (Waddell et al 1993) in respondents. 78 respondents completed the FABQ section of the questionnaire but four all missed one component and were therefore excluded from the analysis (in absence of guidance on how to manage missing values or obvious alternative approaches).

45

Figure 12: Count of total FABQpa scores (n=78)
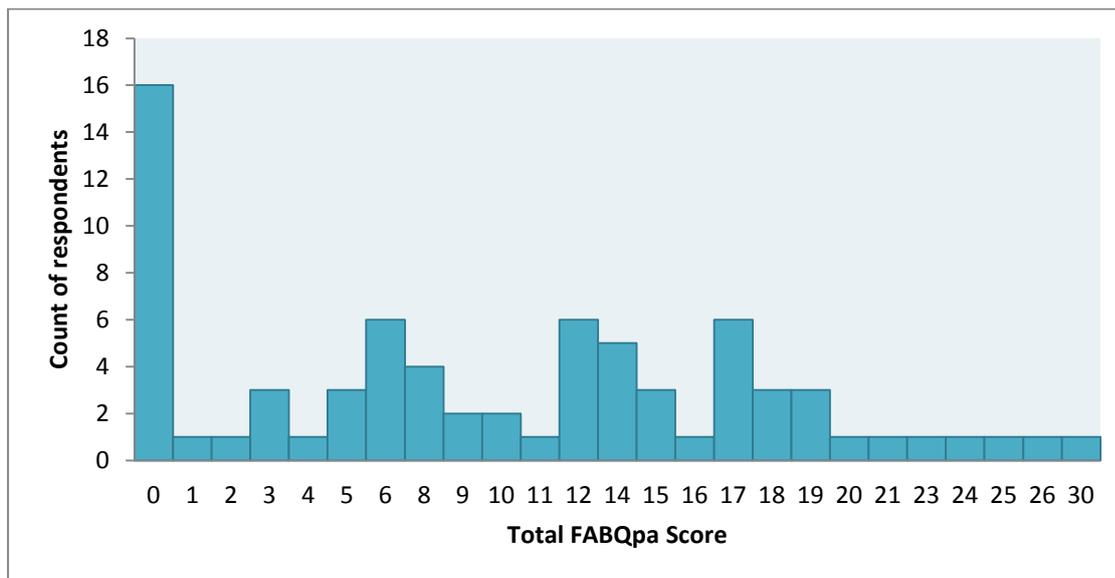
Although 16 people reported a FABQpa combined score of 0 (indicating no fear avoidance beliefs), there was a range of FABQpa total scores across the remaining 58 respondents indicating the presence of fear-avoidance beliefs. Williamson (2006) in her commentary of the FABQ highlights that "*there are no values to define what constitutes an elevated FABQ score*" (p149). Crombez et al (1999) and Roaldsen et al (2009) have taken the approach of considering a FABQpa score greater than the median score of the population studied as an elevated score with stronger fear avoidance beliefs, although Williamson (2006) emphasises that this approach requires further validation to improve the usefulness of the instrument. In absence of other guidance and in line with other authors analysing FAB, this approach was used; the median was 9.5 and therefore weaker fear-avoidance beliefs were considered to be from 0 – 9 and stronger 10 – 30.

60

Williamson (2006, p.149) states that it is important that FAB should be assessed "*so that treatment can address unhelpful beliefs that may contribute to the development or maintenance of disability*". Therefore responses to each individual item on the FABQpa have been reported to provide an indication for clinicians as to the areas where people with AF may have such unhelpful beliefs and these are shown in Figure 13 below.

Figure 13: Frequency of responses to FABQpa for each question
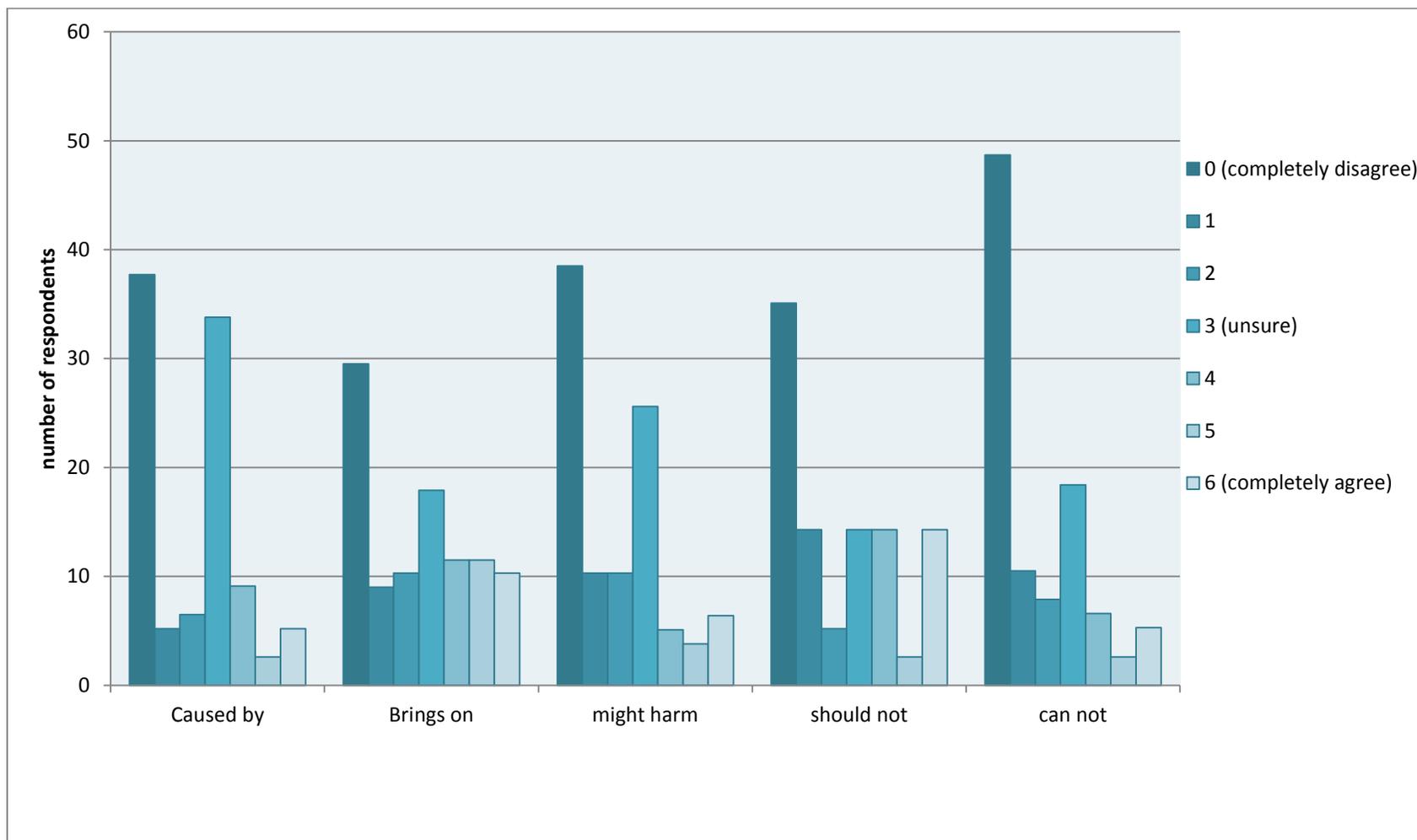
(See Appendix E5: Final questionnaire for questionnaire with full details of each statement.)

9.6 Physical activity, exercise and hobbies

In addition to questions from the FABQ and GPPAQ, respondents were also asked questions about how having AF had affected daily activities and physical activity/exercise. Figure 14 shows the findings.

Figure 14: How AF affected daily activities and physical activity/exercise
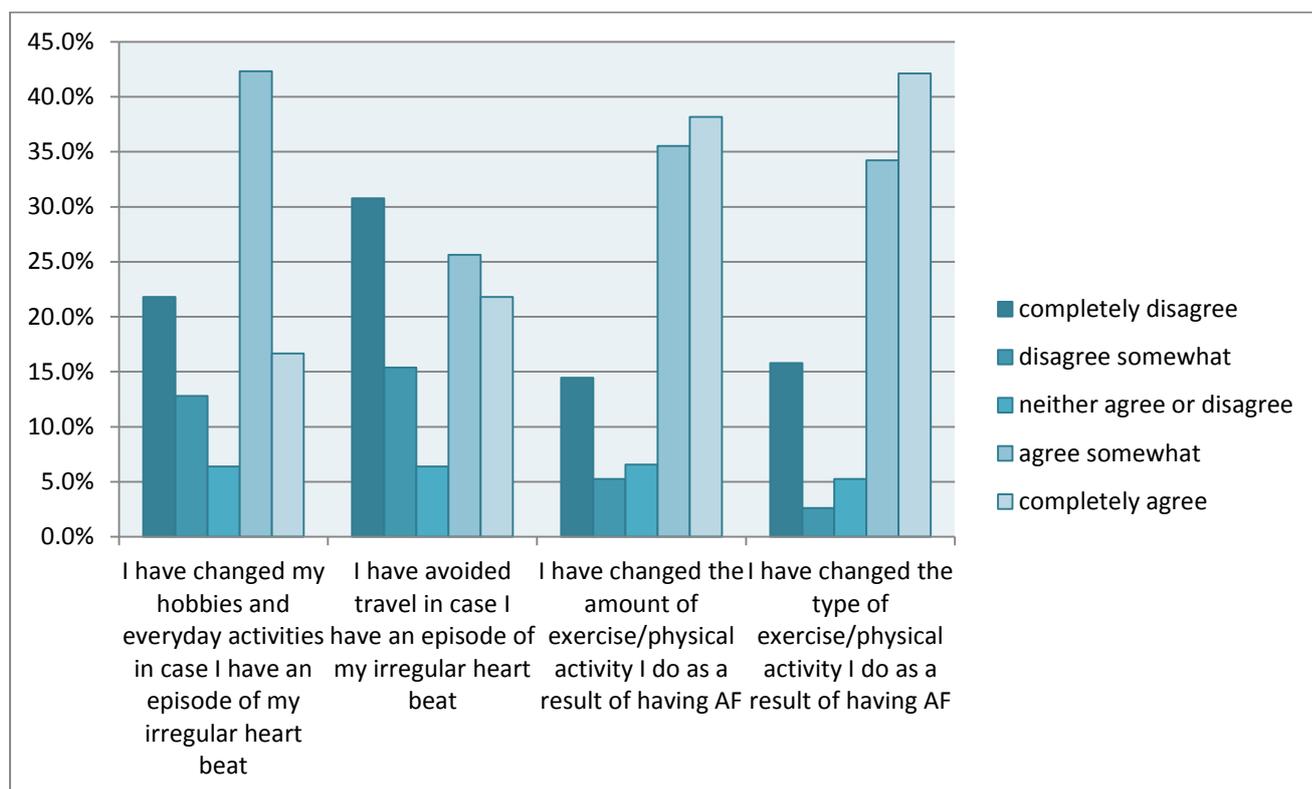
75

9.6.1 Physical Activity, Exercise, Hobbies and Everyday Activities

As a result of having AF, 73.7% of respondents reported that they agreed to some extent, they had changed the *amount* of exercise/physical activity they do (35.5% agreed somewhat and 38.2% completely agreed) and 76.3% that they had changed the *type* of exercise/physical activity they do (34.2% agreed somewhat and 42.1% completely agreed). This indicates that AF has had a noteworthy effect on respondents' physical activity/exercise habits.

As for types of support, to examine relationships between categorical variables, statistical analyses were performed using Fisher's exact test. Analyses were carried out as described in the Data analysis section on page 128, with the ɤ statistic used to assess the strength of relationship between ordinal variables and Cramer's V test

used to measure the strength of association when one of the variables was a nominal variable. Findings are shown in Table 25 on page 159

90 *Statistically significant findings*

There were statistically significant differences between change in amount of physical activity/exercise and symptom severity (p<0.001, ɣ=0.701), symptom frequency (p=0.009, ɣ=0.597) and FAB (p=0.003, ɣ=0.503). The ɣ statistic indicated a moderate relationship between change in amount of physical activity/exercise and these three variables.

There was also a statistical difference between change in type of physical activity/exercise and symptom severity (p=0.004, ɣ=0.606). The ɣ statistic also indicated a moderate relationship between these two variables.

As with levels of need for support, there is little theory to confirm these relationships but the idea that those people with higher symptom severity, more frequent symptoms or stronger FAB would need support is plausible and supported by the moderate relationship indicated by the ɣ statistic.

Findings indicating an association

As with levels of support, relationships between variables approaching levels of
105 significance (p≤0.05 but> 0.01) were also reviewed. There appeared to be an association between change in type of physical activity/exercise and symptom frequency (p=0.012, ɣ=0.535). Study participants who never experience symptoms tended to completely disagree that they have changed the type of PA/E whereas those with occasional/intermediate/frequent symptoms tended to agree somewhat/completely i.e.) those who experience symptoms more frequently had changed the type of PA/E as a result of AF. In the absence of existing evidence, the concept that people with more frequent symptoms would change the type of PA/E they do would suggest that there could be a a relationship between these two variables, supported by the moderate ɣ value.

Symptom severity appeared to have an association with avoidance of travel in case of an episode of AF (p=0.015, ɣ= 0.500). The study data showed that those with no symptoms tended to disagree/completely disagree that they avoided travel in case of an episode of AF whereas those with disabling symptoms agreed/completely agreed, ie) those with more disabling symptoms are more likely to avoid travel in case of an

120 episode of AF (p=0.015, ɣ= 0.500). Once again, in the absence of any established literature this would appear to be a realistic concept supported by a moderate ɣ value suggesting there could be a relationship between these two variables.

Considering duration of AF and avoidance of travel, there appears to be an association between these two variables although the ɣ value is weak (p=0.043, ɣ=0.001). However, study participants with duration of 0-2 years tended to agree/completely agree, as did those with 16+ years of duration but there was a more even spread for the intermediate durations. There is little existing evidence regarding avoidance of travel in people with AF but clinically it may be that those with a more recent onset may not yet have developed confidence in living with their condition and so it is possible that there is an association between these variables but further investigation would be needed to confirm this.

9.6.2 Physical Activity Index

Considering Physical Activity Index, the findings were unclear. The relationship between PAI and classification was approaching significance and Cramer's V

135 indicated a moderate association (p=0.027, Cramer's V = 0.304). Study participants who had persistent AF tended to be less inactive than those with PAF/permanent AF suggesting there could be an association between PAI and classification of AF, although overall, participants had lower levels of activity than the general population (Only 30.4% of the general population were described as meeting "active" levels in 2012 (Department of Health 2012), in this study it is 15.4%). Additionally, the majority of participants in all symptom frequency categories appeared to be inactive, although those with occasional symptoms appeared to be more evenly distributed across all levels of activity and therefore less inactive (p=0.029, ɣ= -0.130). However, there were people in all frequency categories who were active. The overall picture is therefore unclear and this could be an area for further research. Classification, symptom severity, symptom frequency, duration and treatment strategy did not appear to be associated with FAB.

Synopsis - Physical activity, exercise and hobbies and PAI

In summary, symptom severity, symptom frequency and FAB appear to have a clear

150 association with impact on physical activity, exercise and hobbies. Classification and duration also appear to be associated with impact on physical activity, exercise and hobbies.

Table 25: Results of Statistical Analysis for Physical Activity, Exercise and Hobbies

	EHRA Symptom Severity		Symptom frequency		Classification		Duration		Treatment Strategy		FABs	
	p value	Gamma	p value	Gamma	p value	Cramer's V	p value	Gamma	p value	Cramer's V	p value	Gamma
change in H&EA in case causes irregular heartbeat	0.426	0.370	0.212	0.269	0.594	0.210	0.986	0.069	0.601	0.299	**<0.001**	0.697
avoided travel in case have episode of irregular heartbeat	**0.015**	0.500	0.176	0.445	0.194	0.275	**0.043**	0.001	0.843	0.268	**0.005**	0.548
change in amount of PA/exercise as a result of AF	**<0.001**	0.701	**0.009**	0.597	0.691	0.212	0.749	0.038	0.641	0.261	**0.003**	0.503
change in type of PA/exercise as a result of AF	**0.004**	0.606	**0.012**	0.535	0.481	0.230	0.449	0.053	0.206	0.433	**0.028**	0.492
Physical Activity Index (PAI)	0.651	-0.222	**0.029**	-0.130	**0.027**	0.304	0.938	-0.093	0.847	0.205	0.761	-0.061
Fear Avoidance Belief Questionnaire (high/low)	0.539	0.181	0.196	0.268	0.469	0.189	0.816	-0.211	0.616	0.242		

9.6.3 Fear Avoidance Beliefs

The analysis of the effect of FAB on physical activity, exercise and hobbies is reported independently of the other study variables due to the fact that the need to analyse its potential impact arose during the study. (For more detail see Data analysis section at page 128) The findings are shown in Table 26 on page 161.

Statistically significant findings

There was a statistically significant difference with a moderate relationship between FAB and avoidance of travel in case of an episode of AF (p=0.005 ɣ= 0.548), i.e.) those with higher fear avoidance beliefs were more likely to avoid travel.

There was also a statistically significant difference and a moderate relationship between FAB and changes in hobbies and everyday activities (p<0.001, ɣ=0.697). Participants with weaker FABs tended to completely/somewhat disagree that they have changed their hobbies and everyday activities whereas those with stronger FABs tended to agree somewhat/completely i.e.) those with higher FABs had changed their hobbies and everyday activities in case they cause an episode of their irregular heartbeat.

Findings indicating an association

Additionally there appeared to be an association between FAB and change in type of physical activity/exercise (p=0.028, ɣ=0.492). In this study, participants with weaker FABs tended to completely/somewhat disagree that they had changed the type of physical activity/exercise whereas those with stronger FABs tended to agree somewhat/completely i.e.) those with higher FABs had changed the type of physical activity/exercise they undertake. Again, whilst there is little evidence to support this association, it seems to be a rational explanation to suggest that there could be a relationship between these variables, despite the ɣ statistic indicating a weak relationship.

Synopsis – fear avoidance beliefs

Overall, FAB appears to have a relationship with avoidance in travel and changes in hobbies and everyday activities as well as with change in type of physical activity/exercise.

Table 26: Results of Statistical Analysis for Physical Activity, Exercise and Hobbies with Fear Avoidance Behaviour

	FABs p value	Gamma
change in H&EA in case causes irregular heartbeat	**<0.001**	0.697
avoided travel in case have episode of irregular heartbeat	**0.005**	0.548
change in amount of PA/exercise as a result of AF	**0.003**	0.503
change in type of PA/exercise as a result of AF	**0.028**	0.492
Physical Activity Index (PAI)	0.761	-0.061

9.7 Ablation

22 people answered yes to the question "have you had an ablation for your irregular heartbeat?" and their demographics are shown in Table 27 overleaf.

Table 27: Study Variables - People who had an ablation

Variable	Frequency	Percentage
Classification (n=22)		
Unknown	0	0%
PAF	14	63.6%
persistent AF	4	18.2%
permanent AF	4	18.2%
	22	100.0%
Symptom Severity (EHRA scale) (n=22)		
no symptoms (EHRA I)	0	0%
mild symptoms (EHRA II)	7	31.8%
severe symptoms (EHRA III)	13	59.1%
disabling symptoms (EHRA IV)	2	9.1%
	22	100.0%
Symptom frequency (EHRA scale) (n=22)		
Never	0	0%
Occasionally	6	27.3%
Intermediate	9	40.9%
Frequent	7	31.8%
	22	100.0%

Variable	Frequency	Percentage
Duration of AF symptoms (n=21)		
0-2 years	1	4.8%
3-5years	4	19.0%
6-10years	11	52.4%
11-15years	1	4.8%
16+years	4	19.0%
	21	100.0%

(One response could not be coded due to incomplete/unclear information)

Treatment Strategy (n=9)		
Rhythm	4	44.4%
Rate	4	44.4%
Both	1	11.2%
	9	100.0%

195   *NB no medication identified for 13 participants as detailed in section* 9.1.2 Treatment
Strategy *on page 134.*

9.7.1 Levels of need – ablation patients

Three specific types of informational support and two types of emotional support
were investigated in respondents who reported having an ablation. Only one
respondent identified no need for both types of emotional support; for informational
support all respondents identified some level of need for support.

For all three types of **informational** support, at least 65% expressed high need for
support, indicating a need for more information regarding type and amount of
physical activity/exercise and when normal physical activity/exercise could be
resumed. Combining this high need with those who described themselves as
medium need for support, at least 80% of respondents who had an ablation felt they
needed more informational support from their healthcare professionals across all
210   three types of informational support.

For **emotional** support, 41% of respondents expressed high need for support for
both feeling apprehensive about being able to take part in their usual
activities/hobbies and feeling worried about whether or not the ablation would be
successful. Considering medium or high need for emotional support, 82% needed

more emotional support regarding feeling apprehensive about usual activities/hobbies (41% medium need and 41% high need) and 68% more emotional support about feeling worried about success of the procedure (27% medium need and 41% high need).

For more details on levels of need for informational and emotional support, see Figure 15 on page 164.

Therefore there appears to be a need for more informational and emotional support for participants who received an ablation as treatment for their AF.

Figure 15: Levels of Need - Patients who had an Ablation
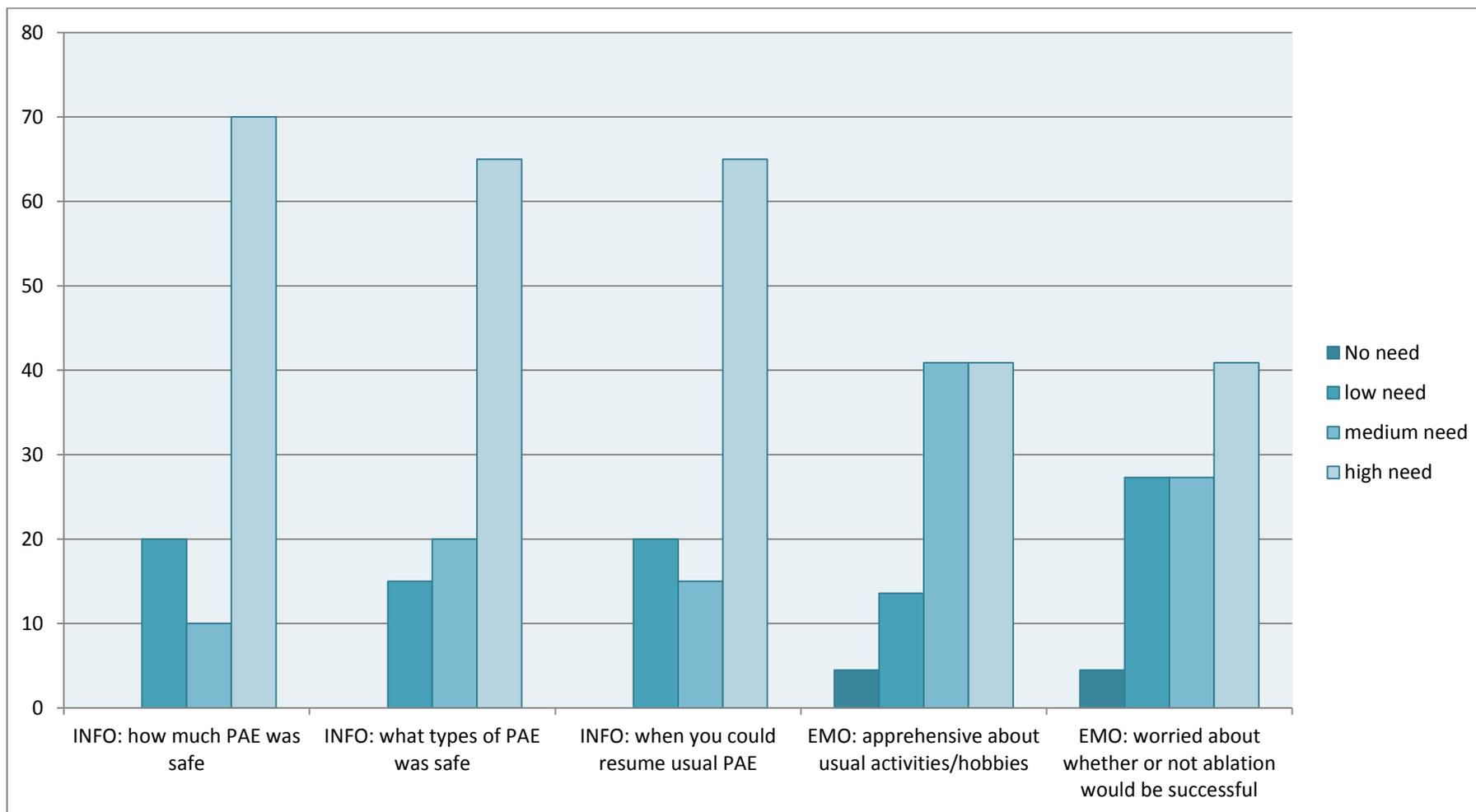
9.8   Health care professionals involved in care of AF

An overview of the range of professionals involved in the care of people with AF was obtained by asking respondents to select which professionals they had seen or come into contact with regarding their irregular heartbeat (see Figure 16 below).

Figure 16: Healthcare Professionals involved in care of AF
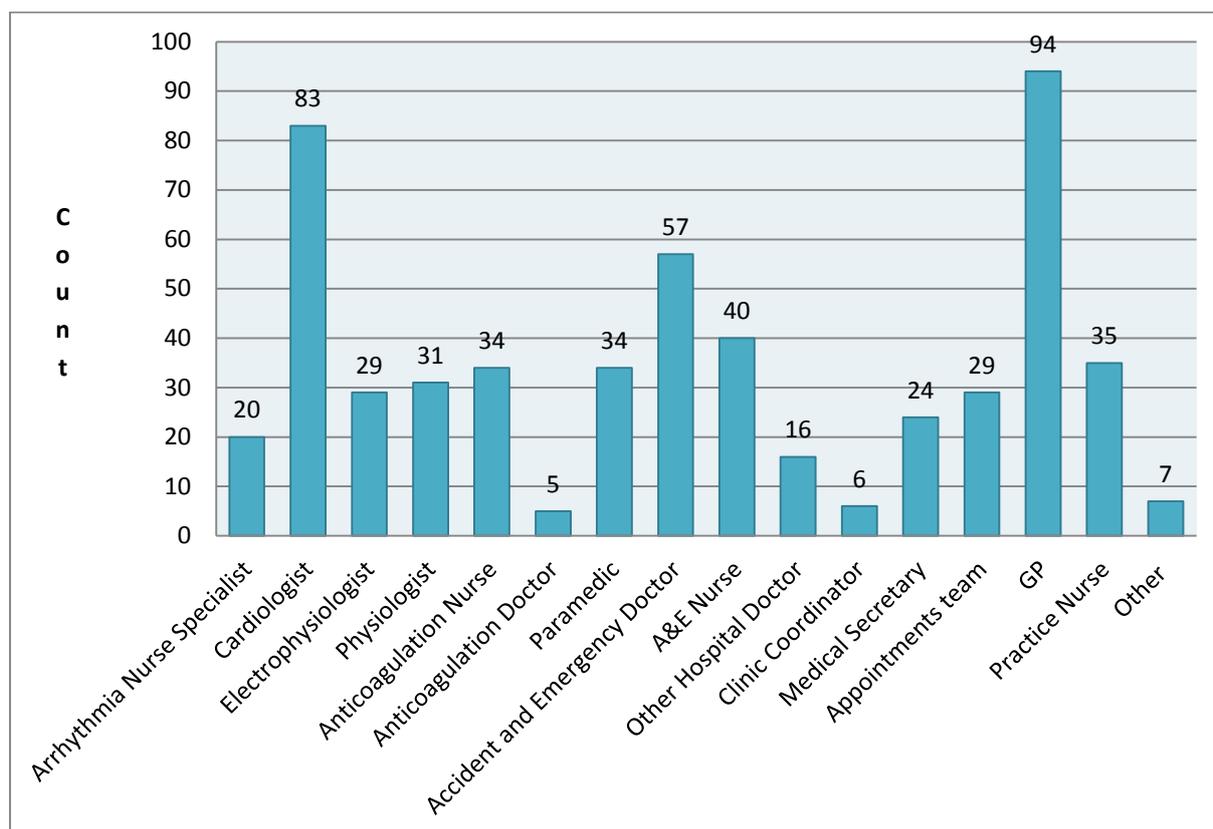
9.9   Most and least supportive health care professional and type of support

Respondents were asked to identify from a list of healthcare professionals, which type of professional had provided them with the most and least helpful support. They were also then asked to detail in free text the nature of this support.

There were 78 responses to most supportive healthcare professional and 73 to least supportive. The professionals most frequently identified as most supportive were GPs, cardiologists and arrhythmia nurse specialists with GPs and cardiologists also most frequently identified as least supportive.

Seven people identified that no health professional had been most supportive and 21 people reported no health professional as least supportive (shown in Figure 17 as "no professional selected")

Figure 17: most and least supportive health care professional
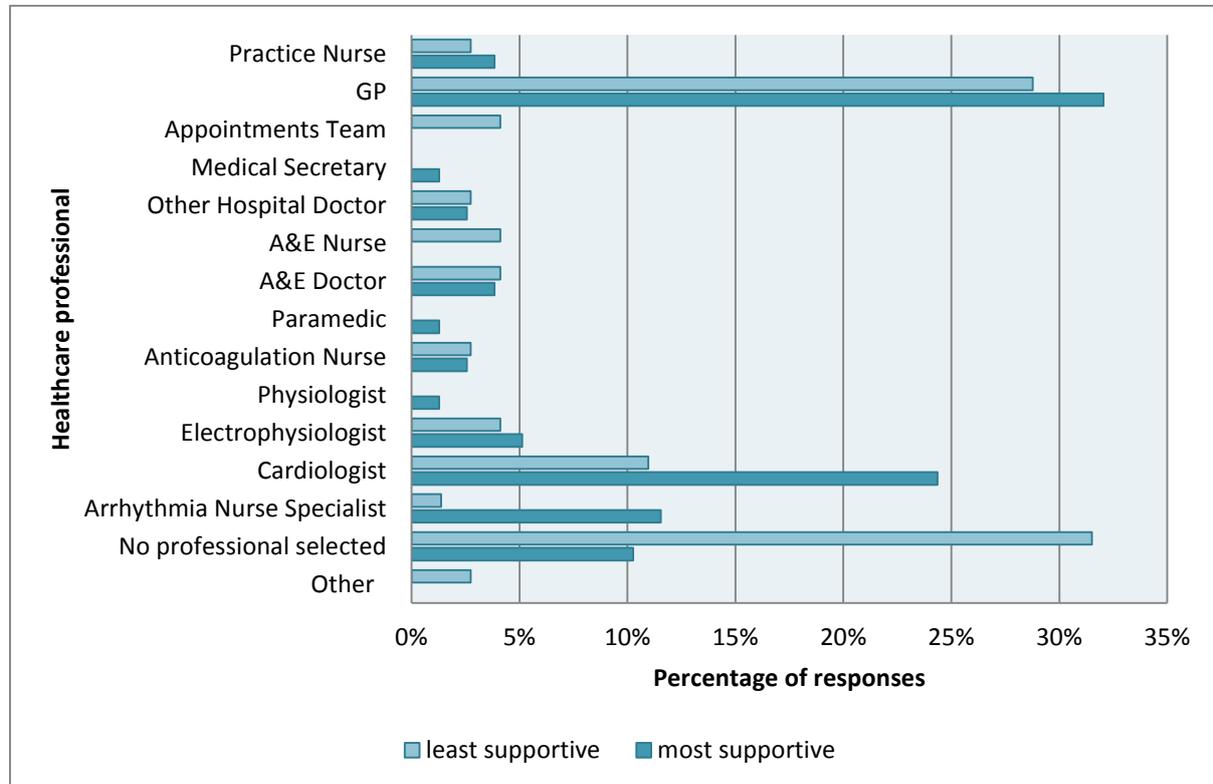
From the free text responses, the type of support was coded using the support framework discussed earlier at page 51. Some people identified a most/least supportive health care professional but did not provide details of the behaviour/action that was most/least supportive which meant the type of support could not be identified; these were therefore coded as "support not described" (n=8 for both most and least supportive).

Figure 18: Most and least helpful type of support provided
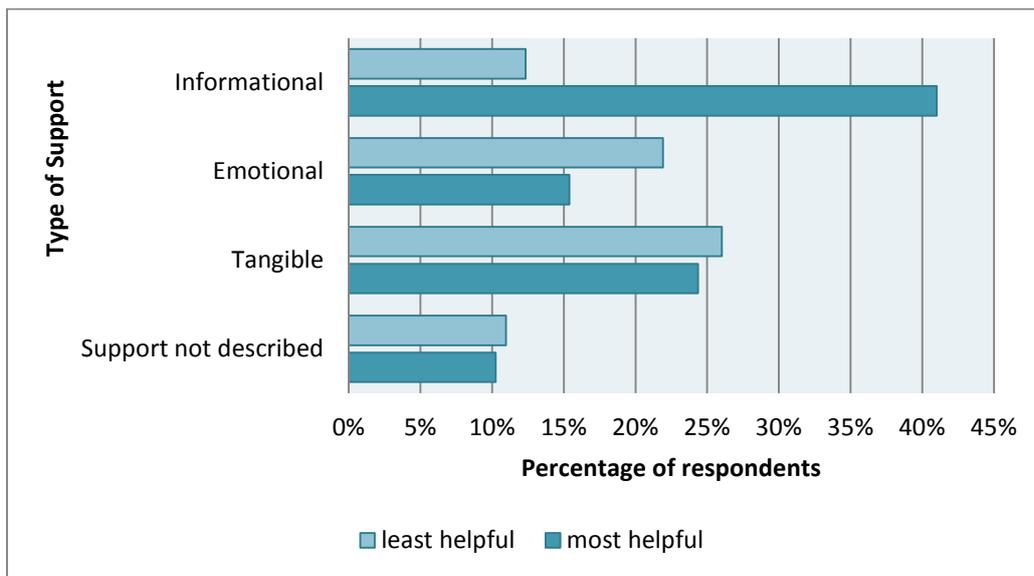
Figure 18 shows that GPs are not only considered as most helpful but also least helpful healthcare professionals and there also differences between the responses regarding cardiologists and arrhythmia nurse specialists (ANSs). Therefore the type of support provided by these professional groups was considered in more detail in Table 28 overleaf.

Table 28: Most helpful and least helpful type of support provided by selected health care professionals

	Most Helpful type of support				Least helpful type of support			
	Informational	Emotional	Tangible	Support not described	Informational	Emotional	Tangible	Support not described
Arrhythmia Nurse Specialist	5	3	1	0	0	0	0	1
Cardiologist	10	2	3	4	2	2	4	0
GP	8	4	9	4	5	4	6	6

Whilst tangible support was the most helpful type of support provided by GP, where details of the least helpful type of support from GPs were provided, they consisted of unhelpful tangible support and informational/emotional support. The most helpful support from cardiologists was informational support compared with tangible support as the least helpful. Most helpful support provided by ANSs was across a range of types of support; no detail was provided about the sole occasion when they were described as the provider of least helpful support.

9.10   Other Comments by Participants

At the end of the questionnaire, participants were able to add any final additional comments regarding support in a free text box. The overall themes of comments was that people felt they had not received enough information regarding AF and that tangible support (in the form of competent medical care) was often missing due to a perceived lack of awareness/knowledge in medical professionals. Emotional support in the form of a dedicated team to support patients with AF was also a common theme raised. These issues have all been addressed in the research and so no new information arose from the free text comments.

9.11 Response rates to questions

Throughout the questionnaire, there was an initial decrease in number of people responding to questions; however this then levelled off. 102 people completed the eligibility and consent questions with 78 completing the final questions relating to healthcare professionals and age.

Figure 19: responses to questions
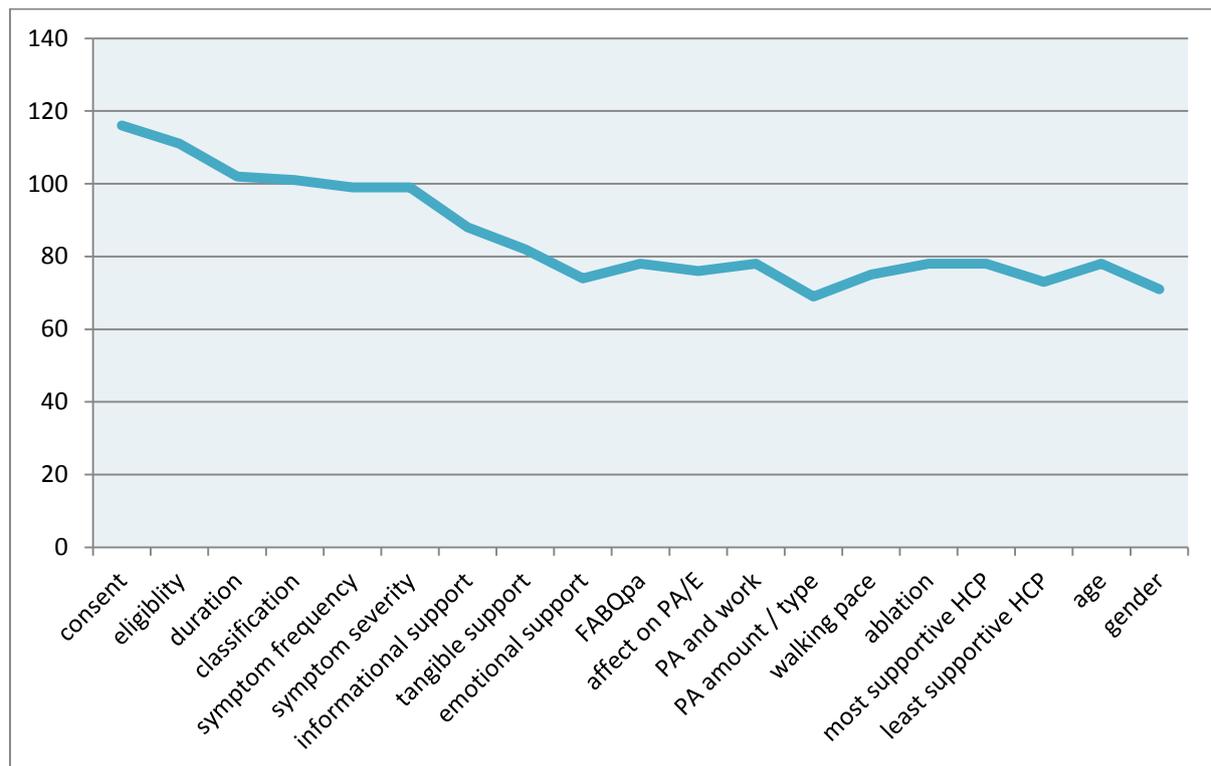
9.12 Summary

This chapter has detailed the findings from the quantitative phase of the study.

Across all three types of support, symptom severity has most association with need for support. Classification is also associated with need for informational support and symptom frequency with need for emotional support. Patients who undergo ablation as treatment for their AF have a need for specific informational and emotional support.

Considering physical activity, exercise and hobbies, symptom severity and symptom frequency have the most effect. Fear avoidance behaviour impacts on all elements of physical activity, exercise and hobbies, with the exception of PAI.

GPs are not only considered as most helpful but also least helpful healthcare professionals and there also differences between the responses regarding cardiologists and arrhythmia nurse specialists.

These findings will be discussed in more detail in the context of other published evidence in chapter ten once issues of quality in this study have been addressed.

10 Quality

Before discussing the findings from the study in light of other research, it is important to consider issues of quality, any limitations of the study and any potential impact on the study findings.

10.1 Rigour, Data Quality, and Validity in Mixed Methods Research

Rolfe (2006, p.309) argue that irrespective of methodology, researchers should "*leave a 'super' audit trail, recounting not only the research decisions taken <u>en route</u>, and the <u>actual</u> course of the research process rather than the <u>idealized</u> version that … is usually presented".* Creswell and Plano Clark (2007 p176) reinforce this view with their description of a rigorous mixed methods study as one that has "*detailed procedures for data collection and analysis, visual diagrams of the procedures, and a strong justification of the use of mixed methods*". However, the issue of how to describe and assess quality in mixed methods research has been the subject of continuing discussion.

In their best practice document for the Office of Behavioral and Social Sciences Research, Creswell et al (2011) highlighted an emergent body of literature about how to assess the quality of a MM investigation and identified that potential approaches for assessing quality in MMR all used different criteria. In 2013, Heyvaert et al reported consensus still to be lacking in this field but highlighted that future work is planned through a proposed international Delphi study to identify the key quality criteria for MMR. However, their review of critical appraisal frameworks used to assess quality in MMR provides a summary structure of criteria developed from the retrieved frameworks using a constant comparative approach, which fall into three main groups; criteria that are explicitly concerned with mixed methods; criteria to score separately the methodology quality of the qualitative and quantitative strands of a study and finally general critical appraisal criteria. As these criteria have been created from an overview of existing frameworks for assessing quality in a systematic approach, it is felt that they provide a robust structure to inform considerations of quality in the current study and the three main groups will be used to address issues of quality and any associated limitations in the present study

10.1.1 Quality specific to mixed methods research

Ongoing debate regarding quality in MMR has maintained the importance of addressing the fundamental tenets of pragmatic mixed methods research; those being that the research question should drive the methods used (Onwuegbuzie and Leech 2005) and that a mixed methods study should be more than just the sum of component phases (Heyvaert et al 2013). This issue is therefore addressed first when considering quality in the current study.

Heyvaert et al (2013) identify two specific criteria for assessing quality in MMR: "*the mixing and integration of the combined methods and strands, and rationales for conducting MMR*" (p.306) and propose that these two criteria should be included in any assessment of quality of MMR. This view is supported by O'Caithin et al (2008) who propose that a good MM study should clearly justify why a mixed methods approach is superior to another, offers transparency of design and appropriate sampling, data collection and analysis of individual components of the design**.** Creswell and Plano Clark (2007) reinforce this view with their description of a rigorous mixed methods study as one that has "*detailed procedures for data collection and analysis, visual diagrams of the procedures, and a strong justification of the use of mixed methods*" (p.176).

This study aimed to identify the professional support needs from the perspective of participants and then to develop a quantitative tool with clinical utility to assess the professional support needs of a wider population of people with AF. The exploratory sequential design adopted for this study clearly provides an appropriate methodology to achieve these aims, therefore justifying the use of mixed methods. (For more detail, see the section Mixed Methods and Instrument Development from page 63.)

Regarding integration of the combined methods and strands, Fetters et al (2013) highlight that integration occurs at the study design level, the method level and the interpretation and reporting level. Through the adoption of an exploratory sequential design, integration has occurred at the design level of this study.

At the method level of integration, Creswell et al (2011) describe this as occurring in four ways: connecting, bridging, merging and embedding. This study has used integration through building ie) when findings from one phase inform the data collection of a subsequent phase, with the later building on the former (Fetters et al

2013). Table 12 shows an extract of how the qualitative data were used to build items for inclusion in the quantitative survey. Mapping of all items can be found in Appendix D: How qualitative data informed quantitative questionnaire.

The third level of integration identified by Fetters et al (2013) regards integration at interpretation and reporting level; this study employs integration through narrative, describing "the qualitative and quantitative findings in a single or series of reports" (Fetters et al 2013, p.2142). A contiguous approach to integration has been adopted in this study which involves presenting the qualitative and quantitative findings in different sections as this is important to demonstrate how the findings from the interviews have informed the development of the questionnaire.

To summarise, the rationale for mixed methods for this study has been clearly articulated with the research question driving the choice of an exploratory sequential design. Through the integration of the two phases at the methods and interpretation and reporting levels, this study is more than its component parts and so this study has addressed the fundamental tenets of pragmatic mixed methods research.

10.1.2 Quality of the individual qualitative & quantitative phases of the study

Teddlie and Tashakkori (2009) proposed that in mixed methods research, data quality is determined by the separate standards of quality in the qualitative and quantitative strands: "*If the QUAL and QUAN data are valid and credible, then the mixed study will have high overall data quality*" (Teddlie and Tashakkori 2009, pp.208-209). They highlight the challenge for mixed methods researchers as there are therefore two different sets of standards for assessing data quality: one for qualitative methods and one for quantitative methods. This appears to be supported by Giddings and Grant (2009, p.120) who propose that "*validation strategies differ depending on which paradigm the study is positioned within*" but this implies separate and discrete research paradigms, not the continuum of research visualised by proponents of mixed methods research described earlier. Giddings and Grant (2009) distance themselves further from the body of work defining mixed methods by going on to describe different validation methods for mixed methods dependent on the choice of research paradigm informing the study but not including pragmatism as a potential paradigm of choice.

O'Caithin et al (2008) feel it is important to consider component parts of a MMR study separately as they each contribute to the study as a whole (p93). Heyvaert et al (2013) propose that the specific strands of a study should be considered as well as the methodological quality of the MM analysis and inferences but highlight that when one strand informs decisions for designing a separate strand, these two strands cannot be appraised as independent.

In this study, it is clear that the two strands cannot be assessed independently as the quantitative instrument is developed from the findings of the qualitative interviews and therefore it is important to acknowledge any limitations from the qualitative phase and their impact on the quantitative phase as well as any limitations from the quantitative phase.

The methods section for the qualitative phase has highlighted the issues regarding access to participants and potential selection bias from the role of gatekeepers in identifying potential participants. This is a factor that may have influenced the study given the influence of clinicians over the recruitment of interview participants with the potential for positive accounts of professional support to lead to bias for items for inclusion in the questionnaire. However, both positive and negative experiences of professional support were used to develop items for inclusion in the questionnaire which would have negated any such impact. Additionally, to minimise any potential gatekeeper effect, the findings from the interviews were checked for face validity and content validity with clinical experts in the field as well as the patient panel with no apparent issues identified. (For more details on this process, see the section "Advice from experts and informants" on page 117)

Mays and Pope (1995, p.110) highlighted that the basic strategy to ensure rigour in qualitative research is "*systematic and self conscious research design, data collection, interpretation, and communication*". Additionally they stated that qualitative researchers should also seek to achieve two goals: reporting an account of the methods and data so that another researcher could analyse the same data in the same way and come to the same conclusions and also constructing a "*plausible and coherent explanation*" of what is being studied. The detailed methodology and findings sections of this study help achieve these two goals.

Creswell (2009) reported that it is also important for qualitative researchers to check that their approaches are consistent and reliable. He proposed checking of transcripts, constantly comparing data with codes and cross-checking codes developed by different researchers. Clearly in this study, there was only one researcher developing the codes but these were cross-checked continuously against the framework of professional support developed from the work of other authors to ensure that a consistent approach was used throughout. Where there was any uncertainty as to how to code data, this was discussed at meetings with the supervisory team and a suitable approach agreed.

Transcripts were reread on several occasions and compared with the original recordings to ensure there were no transcription errors. Additionally the data was read and revisited as the themes were being developed and the findings written to ensure that there was a consistent approach to coding and no drift in definition (Creswell 2009, p.190).

Lincoln and Guba (1985), Mays and Pope (1995) and Creswell (2009) all also drew attention to the importance of clarification of the bias the researcher brings to the study. This is detailed below for the overall study in the section "The impact of the investigator" (page 177). These authors also highlighted the presentation of deviant or negative cases in the findings of the study stating how the discussion of contrary findings adds credibility to the account of the study. Contrary findings were reported in the findings of this study demonstrating the presentation of "negative cases" and supporting the credibility of the study.

Lincoln and Guba (1985) introduced the notion of 'trustworthiness' into qualitative research as important to evaluating its worth. This notion of trustworthiness having confidence in the truth of the findings, showing the applicability of the findings in other contexts, showing the findings to be consistent and able to be repeated and detailing the extent to which the findings are shaped by respondents and not any researcher bias. This current section of the dissertation and the detailed methods and findings sections of the qualitative phase of this study have aimed to address the issue of trustworthiness in this study.

Considering the quantitative phase, selection bias is a potential limitation given the approach of recruitment through the AFA as gatekeepers and the online nature of

the questionnaire. These issues are detailed in the section "Sample population" (from page 112). As detailed earlier, health information seeking behaviour online and support group membership is thought to be higher in women than men, although in this study there is little difference in gender in respondents for both phases. There were eight male and six female participants at the interview phase with 35 male and 36 female participants answering the gender question in the quantitative phase. It is important to recognise that although there are potential sources of bias for selection to both phases of the study, the recruitment methods adopted provide an indication of the professional support needs for people with AF, which is currently lacking in the literature.

Response rate is also a potential limitation of this study. As stated in the methods section for the quantitative phase, there is little evidence to indicate possible response rates for health related studies recruited from a charity membership. It is also difficult to calculate the exact response rate for this study given that there is no reliable method of identifying how many of the AFA members actually received and opened the email inviting them to participate in the study. It is possible that the small numbers of people responding to this study may just have been those people with support needs although the range of responses to questions suggests that it was completed by people with a variety of professional support needs.

Validity and reliability are well recognised to be of importance for quantitative studies (Bryman 2008 and Creswell 2009). Where possible, items were selected for the questionnaire that had already well- established validity and reliability such as the GPPAQ (Department of Health 2009). However, given that this study was addressing an area which has not previously been extensively investigated, items were developed specifically for use in this questionnaire. Face validity and content validity of the questionnaire were confirmed using experts and informants as detailed above. This study gives an indication of the acceptability of these items for use in investigating professional support needs and issues specific to physical activity/exercise for people with AF but these items will need further testing to confirm validity and reliability for future use.

Although the findings from this study provide an indication of the professional support needs and physical activity behaviours of people with AF, given the potential

selection bias from the recruitment methods, more investigation is required before these findings can be generalised to the wider population of people with AF. However, the methods adopted during this study have been clearly described and as such provide an indication of the quality of the qualitative and quantitative components.

10.1.3 Generic Quality Issues

Heyvaert et al (2013, p315) incorporate the issues that address "methodological rigor" in this category of generic criteria including: the theoretical framework, research aims and questions, sampling and data collection, data analysis, context, impact of investigator, transparency, design and interpretation, conclusions, inferences and implications.

The theoretical framework, research aims and questions, context, sampling & data collection, data analysis, context and design have been clearly articulated earlier in the methodology and methods sections of this document. Transparency has been addressed through clear descriptions of the procedures adopted in the study (Bryman et al 2008 and Creswell & Plano Clark 2007), leaving only the issues of the impact of the investigator and interpretation, conclusions, inferences and implications.

The impact of the investigator

Tashakkori and Teddlie's (2003) definition of pragmatism quoted in the Mixed Methods and Pragmatism section (page 59) acknowledges that the values of the researcher play a large role in the interpretation of the results. Later work by the same authors expands the influence of values:

> *"Pragmatists decide what they want to study based on what is important within their personal value systems. They then study that topic in a way that is congruent with their value systems" (Teddlie and Tashakkori 2009, p.90).*

Bryman (2008) says that it is important to acknowledge that the "*values (of the researcher) can materialize at any point during the research*" (p.25) and proposes recognition and acknowledgement of these values and exhibiting reflexivity about the part they play as a method to address their influence.

Reflexivity is defined by Cohen and Crabtree (2006) as "*an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process".* Reflexivity has been described as "*An examination of the filters and lenses through which you see the world*" (Mansfield, 2006) and "*the knower's mirror*" (Malterud 2001, p.484). Greenaway (2014) says that reflexivity helps the researcher "*to explore, learn and understand*" what they are bringing to their research and how this may influence it. Watt (2007) considers reflexivity to be essential as it facilitates understanding, not only of what is being studied but also of the research process itself.

However, Teddlie and Tashakkori (2009, p.90) state that pragmatists "*see no reason to be particularly concerned*" about the role values play. Despite taking a pragmatic approach to this study which would suggest no need to be concerned regarding values and their influence, I felt it was important to acknowledge the values I felt to be central to the development and analysis of this research study to ensure their influence on the study was recognised.

My values as a researcher have been based on both my previous experience as a physiotherapist and my current role as a service improvement manager as well as on personal experience. Although physiotherapy takes a holistic approach to the whole person, it is still very biomedical in approach with an emphasis on measurement, testing and goals for progress (acknowledging that this may have changed since I last practised clinically). At Masters level, my research had been quantitative and therefore before beginning the DHRes, I had very little experience with qualitative research and so felt most comfortable with the concept of quantitative research as a methodology.

However, in my role as service improvement manager, growing political emphasis on patient involvement and patient experience meant that I had already worked with patients and the public to find out their views on specific areas of cardiac care and through this, I had seen a difference between what patients felt to be important and what medical staff felt was important. Despite Chapter Eight of the CHD NSF being very patient focused with emphasis for "*ongoing support with active self-management*" (Department of Health 2005a, p.8), in reality, I felt that the biomedical

model was continuing to dominate what type of care was provided for people with AF.

In addition, I had personal involvement with AF through being a family member to more than one person with AF which broadened my professional perspective and reinforced the feeling of the need to highlight the experience of people with AF. Recounting the experience of one family member to a colleague, my colleague said *"we see so many patients with AF after cardiac surgery that it seems normal to us, we need to think about how scary it is for them".* As a result, it was important to me that patients' voices informed and directed my research to ensure the outcome from the study would be patient focused and not clinician directed. Therefore, it is apparent that my values had a clear influence on the initial design of the research study.

One of the challenges I experienced during my research that I had not anticipated was the tension of these experiences as a researcher, healthcare professional and family member of a person with AF. In the first interview, the participant reported wanting more information regarding weight loss and AF, a field in which I had direct clinical experience that would be of use to the participant and could address their concern. I felt very conflicted due to the fact that as a healthcare professional, I wanted to provide support and advice but I was only in contact with the participant in the role of a researcher. Therefore, I felt it was most appropriate not to provide specific clinical advice and instead directed the participant to the AFA for more information. I felt a similar discord when another participant described his uncertainty as to what he should do given he was experiencing an increase in AF symptoms. As a researcher, this clearly highlighted the lack of informational support as to what he should do if his symptoms changed but as a healthcare professional, I was concerned that he may need to have a clinical review sooner than his next scheduled follow up appointment. On this occasion, I did take more of an active role by asking if he had another appointment booked with the consultant. The participant responded;

> *"He's given me a year in between appointments now so I don't know whether I should phone his secretary up and ask for another appointment" (P106)*

In response to this, I replied that "*I'm on the research side but I think if you are feeling concerned you should ring*". Reflecting on this after the interview, it seemed that the healthcare professional in me felt the issue was important enough to intervene but also that wanted to make sure that I wasn't seen to be giving advice in my healthcare professional role as I was there as a researcher, demonstrating again the challenges of being both a healthcare professional and researcher.

This "role duality" is highlighted by Brannick and Coghlan (2007) who described how insider researchers are likely to encounter role conflict and find themselves caught in identification dilemmas. Marshall and Edgley (2015) described the exact situation of an unexpected question arising which "prompted a desire to explain from a 'physiotherapist perspective'", suggesting that this is not an unusual situation for researcher practitioners.

Throughout the interviews, I also found many occasions when the participant's narrative highlighted how similar my experience was of being a family member to a person with AF, particularly when participants were recounting the impact of their condition on their family. I made a conscious decision not to disclose this to the interview participants as I wanted to ensure that their time was spent focused on their experience and not on mine. However, when one participant revealed that she kept her episodes of AF from her daughter as she didn't want to worry her, this particularly resonated with me. Therefore I did reveal the fact that I had family members with AF who didn't tell me about all their episodes. This participant also asked why I had chosen this subject as my research project so again I shared the fact that I had family members with AF as one of the reasons for choosing this study. Reflecting on this after the interview, I did not think that my disclosure had influenced the course of the interview as I had initially feared. However, I decided that in future interviews, my preference would be not to share this fact as I felt quite conflicted having both the roles of a researcher and a family member at the same time.

These examples show how the experience I have as a healthcare professional and family member of a person with AF influenced my attitudes and behaviours as a researcher in this study. By reflecting on how I had reacted during interviews I was able to understand what my values and experiences brought to the research and any potential influence. Overall I felt strongly that the study had to reflect the lived

experience of people with AF to identify how best to provide high quality care for this patient group and so I was keen to ensure that patients' narratives provided an accurate account of their experience, tending therefore to try and minimise any potential impact by disclosing my experience with AF to participants.

This feeling of the importance of the voice of people with AF continued through the study and at one point, led me to contemplate whether to focus solely on writing up the qualitative experience of people with AF to ensure participants' stories were heard in full. However, it was also important to me that there was a way of influencing clinical practice through a mechanism of identifying the professional support needs of patients with AF and therefore I continued with the original plan of developing a questionnaire which could be used in the clinical setting to inform the care of people with AF.

Reflecting on participants' responses to questions also led to the inclusion of questions relating to physical activity as identified during interviews. Physical activity and its potential to improve health is an area of personal interest (forming the topic of my MSc dissertation) and this was therefore clearly an example of where my values as a researcher influenced the interpretation of the findings. This has a clear fit with Tashakkori and Teddlie (2003)'s acknowledgement of the role of values of the researcher at the stage of interpreting the findings. It may also be that given participants were aware of the fact that I was a physiotherapist from the participant information sheet (see Appendix C3: Qualitative Participant Information Sheet) and specifically raised the issue of physical activity/exercise as a result.

It is clear that both my background and experiences have played a key role in all stages of the study as detailed by Malterud (2001, pp.483-484):

> *"A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions"*

Therefore, a different researcher may discover different but equally valid representations of the support needs of people with AF which would add to an increased understanding of these needs. However, as there is little current evidence

of the needs of this group, the findings from this study will provide initial intelligence which can be further developed by subsequent research. This again has a close fit with using pragmatism as an underpinning approach for this study.

> *"Pragmatists believe that research on any given question at any point in time falls somewhere within the **inductive-deductive research cycle**."* (emphasis by initial author) (Teddlie and Tashokkori 2009, p.87*)*

10.1.4 Interpretation, conclusions, inferences and implications.

Creswell and Plano Clark (2007) defined validity within a mixed methods context as "*the ability of the researcher to draw meaningful and accurate conclusions from all the data in the study*" (2007, p.146) but they identified there is a need for future work to address the issue of validity in mixed methods research:

> *"How should validity be conceptualized in mixed methods research? What does mixed methods validity look like from a pragmatic viewpoint?"* (Creswell and Plano Clark 2007, p.190).

Teddlie and Tashakorri (2003, p.36) stated that validity has become a "catchall term that is increasingly losing its ability to connote anything" and instead they later proposed the term "*inference"* for mixed methods studies, describing this as "*The researcher's interpretations and constructions of what their participants have expressed*" (Teddlie and Tashakorri 2009, p.288).

Onwuegbuzie and Burke Johnson (2006) also agreed that the use of the term validity could be counterproductive and proposed that validity in mixed methods research should be called "legitimation" in order to use a "bilingual nomenclature" that is acceptable to both qualitative and quantitative researchers (p.55). They suggested that legitimation checks should occur at each stage of the research and should be seen as a continuous process as opposed to the work of Teddlie and Tashakorri (2003) relating to inference quality which Onwuegbuzie and Burke Johnson (2006, p.56) described inference as "an outcome".

However, both models highlight the importance of consistency between research purpose, research questions and research design, inferences made and the methodological quality. Teddlie and Tashakorri (2009, p.286) proposed that:

"the most important step in any MM study is when the results (i.e., findings, conclusions) from the study's QUAL and QUAN strands are incorporated into a coherent conceptual framework that provides an effective answer to the research question"

They also suggested that to make credible inferences it is important to keep the research purpose and questions at "the foreground of all …analyses and interpretations" (Teddlie and Tashakorri 2009, p.291) as well as addressing the fact that the strength of a good mixed methods study depends on "the extent that it fulfils the purpose for using those methods" (Teddlie and Tashakorri 2009, p.292).

This study aimed to identify and assess the professional support needs of people with AF by: examining these needs through qualitative interviews; developing a patient-centred questionnaire; establishing professional support needs across a population of people with AF; considering any differences in support needs in relation to symptom severity, classification, treatment strategy and duration of AF; investigating the beliefs regarding physical activity and AF and the impact of AF on physical activity behaviour as well as contributing to the evidence base on professional support needs of people with AF. (See page 16 for study aims and objectives in detail)

In order to develop a quantitative instrument that reflected the views and needs of people with AF, this study used a mixed methods approach with an initial qualitative phase to inform the content of the questionnaire. Instrument development has been acknowledged as an appropriate topic for investigation using mixed methods research (Creswell 2009 and Tritter 2007) especially when there is little available literature to inform content (Kroll and Neri 2009) as was the case in this study.

The theoretical framework of professional support has guided and informed inferences made in the data analysis and interpretation of each phase of the study. However, issues relating to physical activity have also been included as they arose from the interviews, demonstrating how inferences and interpretation have been made on a continual basis throughout the study. The conclusions from this study will be addressed in the next chapter of this document.

10.1.5 Legitimation

Onwuegbuzie and Burke Johnson (2006) highlighted that there are some specific problems of integration in mixed methods research not associated with monomethods studies which are not addressed in the inference framework proposed by Teddlie and Tashakorri (2009). They outlined a typology of nine legitimation types, with the most relevant of these nine legitimation types to address as a potential limitation of this study is sample integration legitimation[12]. Onwuegbuezie and Burke Johnson (2006) described this as applying to situations in which a researcher wants to make statistical generalisations from the sample participants to a larger target population and that if different groups are used in the different phases of a study, "*constructing meta-inferences by pulling together the inferences from the qualitative and quantitative phases can be problematic*" (p.56). Therefore it is important to consider if there are any differences in the composition of participants for the qualitative and quantitative phases, to establish any differences and to understand whether these are in line with the wider AF population.

There are some differences in demographics of the participants in the different phases of the study. The percentage of participants with PAF at the interview phase is higher than that in the questionnaire phase. Little is known about the classification of AF of people who attend hospital appointments although Dorian et al (2000) reported that therapy to restore and maintain sinus rhythm for patients with persistent or PAF (described collectively in their study as intermittent AF) is often ineffective and therefore "*many patients with intermittent AF are referred to tertiary care referral centers*" (p.1303). It is important though to acknowledge that tertiary centres are district hospitals for their local population and for nine out of the fourteen interview participants the recruiting tertiary centre was their local hospital, suggesting that these interview participants did not fit this description by Dorian et al (2000).

Camm et al (2010, p.2377) describe how AF progresses from "*short, rare episodes, to longer and more frequent attacks*" and how over time patients will develop more sustained forms of AF. It is therefore possible that the higher percentage of interview participants with PAF was due to them having developed the condition more recently and being referred to their local hospital for initial diagnosis and support as opposed

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[12] For details of the other types of legitimation and how they are addressed in this study, see Appendix J

to being referred to a tertiary care centre for more difficult to manage ongoing AF. This would appear to be supported by the higher number of interview participants reporting a duration of 0-2 years.

However, reviewing the literature, it is difficult to accurately ascertain population sizes by classification of AF. In an editorial piece relating to an article on paroxysmal atrial fibrillation, Smith et al (2010) reported paroxysmal atrial fibrillation comprising of 25-62% of cases seen by physicians and GPs. However, further examination of the studies cited to support this claim show one to be an observation of only 234 patients with atrial fibrillation of which 94 (40.2%) were paroxysmal (Takahashi et al 1981). The second study cited is a report on the epidemiological data pertinent to atrial fibrillation collected in the Framlingham study (Kannel et al 1998) which appears to report on the combined groups of what was then described as paroxysmal and chronic atrial fibrillation, rather than to separate out percentages in each group.

Stewart et al (2001) took a similar epidemiological approach to Kannel et al (1998) and reported on the data relevant to atrial fibrillation from another large population cohort. In their study, a single ECG recording was performed at baseline and again four years later from which the presence of atrial fibrillation was identified. However, the authors highlighted that this methodology does not allow for them to differentiate between paroxysmal and sustained atrial fibrillation (Stewart et al 2001) but point out that this limitation also applies to other studies.

Some studies of patients with atrial fibrillation provide an indication regarding the classification of AF of participants although the different inclusion criteria and populations being investigated in individual studies and the limitations of longitudinal studies in recording classification of AF mean that it is difficult to ascertain whether the study samples are representative of the wider population of people with AF. Thrall et al's (2007) study recruited from a specialist atrial fibrillation clinic reported 52.5% of participants with paroxysmal atrial fibrillation, 5.9% persistent atrial fibrillation and 41.6% permanent atrial fibrillation. Dorian et al (2000) also recruited from outpatient arrhythmia clinics at tertiary hospitals for their study of patients with intermittent atrial fibrillation which recruited patients with either paroxysmal or persistent atrial fibrillation. They found 60.5% of participants to have paroxysmal

atrial fibrillation and 39.5% persistent atrial fibrillation. However, patients in permanent atrial fibrillation were excluded from their study.

Therefore it is not possible to identify whether the study populations are similar to or different from the overall population of people with AF with regard to classification. As detailed earlier in the section "Sample population" (from page 112), health information seeking behaviour online and support group membership is thought to be higher in women than men, although in this study there is little difference in gender in respondents for both phases. There were eight male and six female participants at the interview stage with 35 male and 36 female participants answering the gender question in the quantitative phase.

Considering age of participants, there appear to be higher percentages of interview participants in the younger age groups although overall, the spread of participants appears to be spread across all age groups in a similar manner in both phases of the study. Considering duration of AF, there appeared to be higher percentages of interview participants with a shorter duration of AF.

To summarise, it is difficult to describe the demographics of the overall population of people with AF and therefore to consider whether the participants of each phase are similar to or different to the wider population of people with AF. Although there are some differences between the participants of both phases of the study, these differences were not felt to have impacted on the findings due to the sequential nature of the study design. As little is known regarding the specific demographics of the overall population, further epidemiological research would be needed to support generalisation of the findings to the wider population of people with AF.

It is important to recognise that this study provides an initial indication into the professional support needs of people with AF, an area that to date has not been investigated in any detail. Further research will be required to confirm how applicable the findings of this study are to the wider population of people with AF. However, the findings of this study do highlight that there is a need for professional support for people with AF to enable them to live with their condition, to minimise the impact of their condition and to improve their experience of health services.

10.2 Patient and Public Involvement

One of the issues not identified in Heyvaert et al's (2013) review of frameworks for appraising quality in mixed methods research is public and patient involvement in the research. This issue is now explored in more detail, given the involvement of patients/public is believed to lead to higher quality research of more clinical relevance (Boote 2002 and INVOLVE 2004)

This research study has taken a mixed methods approach to ensure that the voice of patients is integral to the study. As described in the chapter "Overall Methodology for Study", the use of qualitative research to inform the development of the questionnaire ensures that the research is "grounded in the experience of those who are *the object of the study*" (Tritter 2007, p.302), reflects the "*typical vocabulary*" of the subjects of the survey (McColl and Thomas 2000, p.15) and has an understanding of the "*cultural milieux*" of the study population (Onwuegbuzie et al 2010, p.63). This has a close fit with the model proposed by Stewart and Liabo (2012) promoting the use of public expertise at the stage of identifying research topics and questions.

10.2.1 Involvement in development of this study

At different stages of the study, various approaches were taken to ensure that there was appropriate public involvement and to ensure that this involvement was used to inform the development of the study. These approaches are described throughout the methodology of the study but are detailed here to illustrate how public involvement has influenced and informed the research.

Initially my experience as a family member of a person with AF and also my role in delivering services for people with AF was influential in deciding the topic of the study (more in "Reflexivity" section on page 178). This was then sense checked with discussions with an existing cardiac patient and public panel with whom the author was involved in a work capacity. This panel supported the topic of the study as one of importance to patients and therefore the study was developed further.

The same panel was then involved in the development of the interview topic guide for the qualitative phase. Given the lack of literature on professional support for people with AF, the aim of the topic guide was to allow for flexibility to gain a wide understanding and to ensure that the insights of patients were identified to inform the

development of a patient-centred questionnaire. Although supportive of the concept of asking participants to talk about their experience, there was some feedback from the patient panel that questions needed to be more closed and directed to avoid "rambling responses" (personal communication patient panel). This was a practical example of Stewart and Liabo's (2012) notion of researcher expertise being required to choose appropriate methods to inform research design with open ended questions seen as a way of eliciting "*insight into what the interviewee sees as relevant and important*" (Bryman 2008, p.437). The author explained to the panel the rationale behind the choice of open ended questions and the panel accepted this as an appropriate way to proceed.

As described in the methodology chapter, after the first two interviews where both respondents highlighted physical activity and exercise as a specific issue, questions on this topic were added to the interview schedule. Entwistle et al (1998) highlight the added value of the views of patients in research and how patients may provide insights that would otherwise be overlooked. Using an iterative approach to the ongoing development of the topic guide is an additional example of public involvement in the research project.

During the period of analysis and questionnaire development, the role, function and membership of the cardiac patient and public panel had changed and it was no longer appropriate to discuss the research study in this forum. However, whilst working with the AFA to plan for distribution of the questionnaire, the AFA proposed the use their private online forum to recruit an advisory panel to provide further ongoing PPI in the research study and this approach was duly adopted. The AFA posted a message in their online forum inviting people who were interested in being part of the advisory panel to contact the researcher. Fourteen people replied and were sent more information on the research. All fourteen agreed to be part of the panel and were sent an overview of the research and the key themes arising from the interviews and asked to identify if they had any other areas for inclusion. Members identified duration and symptom frequency as areas they felt were important to include in the questionnaire as both may influence the need for support and so specific questions were included in the questionnaire to identify duration and symptom frequency.

Public involvement also informed the pilot stage of the questionnaire. The advisory panel completed the pilot questionnaire which included an additional question to allow participants to comment on ways to improve the design, highlight any ambiguous questions and identify any omissions. The panel were also asked to email the researcher directly with any comments or input. Changes were made to the questionnaire in response to the panel's input and these are detailed in the section entitled "Piloting questionnaire" (page 125).

10.2.2 Impact on findings of study

Nilsen et al (2006) highlight however that there is a lack of research that reliably investigates whether public involvement in research actually achieves the intentions of improving the quality and relevance of research. Brett et al (2012) draw attention to the fact that the increased interest in user involvement makes it important to examine its impact on research. It is therefore important to consider how public involvement impacted on the findings of this study.

The impact of public involvement in this study can be defined into three fields: physical activity; variables under investigation and support after ablation. However, it is also important to acknowledge that as the questionnaire was developed using the findings from the interviews, it is difficult to identify the full impact of qualitative interviews on the overall study. Due to the limited evidence relating to the experience of people with AF, it is likely that a range of issues would not have been included in a questionnaire developed solely from a literature review, with an associated limitation to findings from the questionnaire.

Physical activity is one field where the views of patients have added value to the research and provided insights that would otherwise have been overlooked (Entwhistle et al 1998). Using an iterative approach to the interview topic guide allowed for the inclusion of physical activity and exercise as this arose from the first two interviews. Subsequent interviews identified a fear of exercise and activity and the impact of AF on activity levels. Subsequently, questions on physical activity were included in the questionnaire and showed that AF had a noteworthy effect on respondents' exercise/physical activity levels. Only 15% of study population met recommended activity levels and statistically significant differences were identified between FAB and avoidance of travel and changes in hobbies and everyday

activities (see page 153 for detailed findings). Without the iterative approach to interviews, these physical activity/exercise specific findings would not have been recognised.

The variables used in the questionnaire were also influenced by public involvement in the study with an accompanying impact on findings. Duration and frequency were identified as variables for inclusion through public involvement and whilst duration does not appear to influence support needs, frequency appears to influence the need for eight types of emotional support from professionals and for one type of tangible support. This need for support would not have been identified without the inclusion of frequency of symptoms as a variable. Frequency of symptoms also appears to influence change in type of physical activity/exercise, which again would not have been identified without inclusion of frequency as a variable.

The data values of specific variables were also influenced by public involvement. A lay member of the ethics committee identified the need for the inclusion of a "never" value in the frequency scale to reflect the perspective of those people with silent AF. Only five people selected this option but these people would have been unable to respond accurately to the question regarding frequency without this option which may have distorted overall findings. Specific to levels of need for support, the interviews revealed that this need was a sliding scale rather than a dichotomy and therefore four categories of need were developed: no need, low need, medium need and high need. This allowed for a clearer understanding of people's need for support from healthcare professionals. Fear of heart attack or stroke was separated into two separate items for the questionnaire as a result of public involvement. The findings showed that there is a need for emotional support about the fear of stroke irrespective of symptom frequency and a need for emotional support about the fear of MI irrespective of treatment strategy. These findings would not have been identified if the item had not been sub-divided.

The final field where public involvement influenced the findings of the study is regarding support after ablation. The interviews identified a particular lack of informational and emotional support for people who were treated with an ablation and so specific questions on this issue were included in the questionnaire. At least 80% of participants identified a medium/high need for support across all three types

of informational support. 82% of participants had a medium/high need for emotional support regarding feeling apprehensive about usual hobbies/activities and 68% had a medium/high need for emotional support about feeling worried about the success of their ablation. Without public involvement informing the study, these needs may not have been identified as they are not apparent in existing literature.

In summary, public involvement has influenced the study design through both the qualitative and quantitative phases. This influence has led to the identification of findings that may not have otherwise been generated but all of which are important to consider in the context of professional support for people with AF. From this study, public involvement has improved the quality of the research by adding insights that would otherwise have been missed (Entwhistle et al 1998) and which will improve the condition of the consumer (Boote et al 2002).

10.3 Summary - Quality

Having discussed factors affecting quality, the themes of professional support for people with AF together with beliefs regarding physical activity and the impact of AF on physical activity behaviour will now be discussed in more detail.

11 Discussion

This chapter will consider the findings of the study in light of other research and in the context of the overarching framework of professional support. This study aimed to identify and explore the professional support needs of people with AF and used a framework developed from social support theory to investigate the types of support that people with AF need from professionals involved in their management and care. Issues regarding physical activity and the impact of AF on physical activity behaviours arose from the study and will also be discussed after first considering professional support.

11.1 Professional Support

The findings presented an overview of the emotional, tangible and informational support needs of people with AF as identified from the quantitative questionnaire group. This chapter will consider these findings in light of other research and in the context of the overarching framework for professional support to contribute to the existing body of knowledge. Professional support will be discussed within the wider context of patient experience to demonstrate the importance of effective professional support in the delivery of high quality healthcare.

Government policy in the UK aims to improve the experience of patients receiving healthcare in a drive to improve the overall quality of care (Department of Health 2008; the NHS Confederation 2010, NICE 2012a and NICE 2012b). The importance of support from healthcare professionals to facilitate self-management and self-care is highlighted as key to delivering this improvement in experience. However, there is little evidence regarding both the overall concept and the detailed types of professional support (i.e., the support that patients require from their healthcare professionals) although the literature from the social support field provides some indication, with emotional, tangible and informational support highlighted as the main types of such support (Schaefer et al 1981). A framework for professional support was therefore proposed to inform this study, using these three different types of support.

For people with AF, the evidence relating the support required from healthcare professionals is very limited, even though the importance of such support is accentuated in the arrhythmia specific policy document, Chapter Eight of the CHD

NSF (Department of Health 2005a). This outlines quality requirements aiming to improve the emotional and practical support offered to patients with arrhythmias and emphasises the importance of a formal assessment of support needs for people with arrhythmias as well as the need for people with long-term conditions to receive support in managing their illness from a named arrhythmia care coordinator. Good quality timely information is also identified as important (Department of Health 2005a, p8).

In 2006 the BHF funded 32 arrhythmia care coordinator posts across the country following publication of Chapter Eight of the CHD NSF (Department of Health 2005a); all of these posts were filled by registered nurses (Ismail and Lewin 2010). The evaluation of the funding found that specialist nurses can play an important role in improving the patient experience and in delivering support and information for patients with arrhythmias including AF. The nurses were described as " *a major form of support, providing much needed information, taking time to hear their concerns, and providing explanations and reassurance" (*Ismail and Lewin 2010, p.180*).* However, little information was provided about the exact components of support provided by these specialist nurses. This study specifically investigated these core components of professional support, using a three-dimensional framework of emotional, informational and tangible support to identify the types of support that people with AF need from their healthcare professionals. These elements are discussed individually in more detail now.

11.1.1 Informational support

Using the types of informational support identified in the interviews, ten specific components of informational support were assessed in this study questionnaire with varying levels of need identified by respondents. 80% of all participants reported medium/high need regarding what to do if their symptoms changed, suggesting this should be an integral part of any clinical discussion. Moser et al (1993) identified that informational needs have been ranked in virtually all studies of cardiac patients as having the highest priority. This was reinforced in their study of patients and spouses post-acute cardiac event but their work did not consider patients with an arrhythmic episode.

Considering patients with AF, in a study exploring patients' perceptions of anticoagulation therapy, Lip et al (2002) surveyed patients with AF who had been regular attenders at an anticoagulation clinic in a city centre teaching hospital. The study aimed to identify whether different ethnic groups had different levels of knowledge and perceptions of atrial fibrillation (AF) and of their antithrombotic therapy. They found that "*many patients with AF possess very limited knowledge of AF as well as its consequences and therapy*" (Lip et al 2002, p.242) despite the fact they were regular attenders at clinic. 61% of all participants (with no differences due to ethnicity) described their condition as "*not very serious*" (Lip et al 2002, p.241) and this lack of awareness of the seriousness of AF (given the associated risk of stroke) was described as of some concern by the authors who proposed that this may be a reflection of the poor amount of counselling and information given by healthcare professionals.

Kopenen et al's (2007 p.56) study of knowledge about AF of patients attending the emergency room (ER) also found "*serious flaws in knowledge about AF as a disease (…) and seeking treatment*". At follow up three months after the initial visit to the ER they reported that patients still had only limited knowledge about how to detect AF and how to seek treatment. The authors proposed knowledge to be clearly associated with a patient's sense of well-being and how they coped with AF highlighting the importance of effective informational support. These previous studies highlight the apparent inadequacy of informational support for patients with AF and the importance of the provision of appropriate informational support, which is reinforced by the need for such support identified in this study.

Kopenen et al (2007) also identified that women, older people and those with their first episode of AF had less knowledge about their condition but there was no report of knowledge related to classification of AF in their study. In this current study, classification appeared to be the relevant variable influencing the need for informational support with patients with PAF having a higher need for effective informational support from their healthcare professionals. These findings strongly support the importance of considering classification when identifying the need for informational support and so adds to the knowledge and understanding of informational support in this patient group.

The findings from the quantitative phase of this study indicate the most important type of informational support for people with PAF was related to managing AF at home; people with PAF tended to have a higher level of need for this type of informational support. There also appeared to be an association with classification regarding what to do if they get an episode of their AF, with those with PAF or persistent AF tending to have a higher need for this type of informational support. This need for informational support is possibly due to the intermittent nature of PAF and persistent AF, with participants not sure what to do once their symptoms change*.*

The link between classification and informational support has not previously been identified in existing research and has significant implications for clinical practice. It is important that healthcare professionals provide clear guidance for patients with PAF/persistent AF about how to manage AF at home and what to do if they get an episode of AF. The traffic light approach as used for patients with heart failure (Greater Manchester Collaboration for Leadership in Applied Health Research and Care, no date) could be an effective method of addressing this need for these specific types of informational support as it provides clear instructions depending on the patient's changing symptoms.

This study also appeared to demonstrate an association between symptom severity and informational support regarding how to manage their AF at home. This has similarities with the findings of Kang (2005) who reported that in patients with newly diagnosed AF, greater symptom severity was associated with higher uncertainty and greater appraisal of danger, which was then also associated with the perception of poorer mental and general health. Kang (2005, p.189) therefore concluded that there is "*a need to reduce perceptions of uncertainty as soon as possible to prevent the negative effects that uncertainty has on mental health"* for this group of patients and proposed the need for informational support by health professionals. This current study builds on the work of Kang (2005) by identifying that people with greater symptom severity need more informational support, not just those who are recently diagnosed, and therefore highlights the importance of clinicians identifying levels of symptom severity at initial assessment and ongoing review. The results from this study indicate that such informational support should focus on how to manage AF at home.

There also appeared to be an association between treatment strategy and informational support regarding what to do if symptoms change. Treatment strategy does not appear to have been considered in previous studies looking at knowledge and information needs in patients with AF and so this provides new knowledge with associated implications for clinical practice. In this study, participants with rate treatment strategy tended to have medium to high need for this type of informational support, whereas those with a rhythm treatment strategy tended to have a more even spread of need. Treatment strategy could only be identified in 42 of the participants in the study but the majority of these (55%) were being managed with rate control and therefore the findings indicate that these participants would require informational support of this type. As detailed above, the traffic light approach could provide a mechanism for healthcare professionals to deliver such support to this patient group.

Overall this study has contributed to existing knowledge regarding informational support by identifying specific kinds of informational support that patients with AF would like to receive from their healthcare professionals. It also identifies the fact that classification, symptom severity and treatment strategy all appear to influence the need for informational support with patients with PAF/persistent AF, greater symptoms and rate control treatment strategy all having greater need of such support from their healthcare professionals.

11.1.2 Tangible Support

Hupcey and Morse (1997) proposed that professionals did not provide tangible support for their patients but other authors disagreed, highlighting tangible support as key support from healthcare professionals (Koivula et al 2002; Dakof and Taylor 1990; Warwick et al 2004; Martin et al 1994; Masters et al 2007 and Miles et al 1999). Two sub categories of tangible support were identified in the interview phase of this study and therefore included in the questionnaire: tangible support relating to help with physical tasks and tangible support in the form of provision of medical care. The greatest identified need for tangible support identified in this study was for support from one healthcare professional who could talk about all aspects of their condition, treatment and follow up with 74% of participants expressing medium or high need for such support.

This concept of one healthcare professional who can talk about all aspects of their condition, treatment and follow up exists for patients with cancer with the well-recognised role of key worker. One member of staff, usually a clinical nurse specialist, is identified to the patient and has the responsibility of providing continuity of care and support, offering referral to psychological services if required and liaising with other healthcare professionals (NICE 2011b). A similar role was promoted in the arrhythmia specific chapter of the CHD NSF, where a marker of good practice was identified as "*People with long-term conditions receive support in managing their illness from a named arrhythmia care co-ordinator*" (Department of Health 2005a, p8).

Findings from the evaluation of the BHF ACC awards and a subsequent published paper showed that this type of support was provided to patients with arrhythmias by arrhythmia nurse specialists funded by the BHF (Ismail and Lewin 2010 and Ismail and Lewin 2012). Participants reported the importance of this role being expanded so that all patients with arrhythmias could benefit from such support, which is reinforced by the findings from this study with a unique focus specific to people with AF. As well as the need identified in the questionnaire responses, interview participants also highlighted the key coordination and support provided by the nurse specialists:

> *"Although the Professor is the top man, it was the nurse that ran all over the place for me…. They organised absolutely everything. If they couldn't get the ECG done quick enough, they'd drag you in there and do it themselves" (P103)*

Given the complexity of AF, the fluctuation in symptoms and the long term nature of the condition, this study provides evidence of the importance of one healthcare professional to coordinate the care of this patient group, providing tangible support as well as informational and emotional support. The findings also reinforce the work of other authors described earlier who have proposed that healthcare professionals do indeed provide tangible support to their patients.

11.1.3 Emotional Support

The third type of professional support investigated in this study was emotional support. People with AF have a clear need for emotional support with studies

reporting they have higher levels of anxiety and depression than the general population (Thrall et al 2007) and a lower than average quality of life (Thrall et al 2006). Kang (2005) examined the effect of uncertainty of perceived health status in 81 patients with atrial fibrillation. Greater symptom severity was associated with higher uncertainty and those patients with higher uncertainty appraised a greater danger. Greater appraisal of danger was then also associated with the perception of poorer mental and general health. Kang (2005, p.189) therefore concluded that there is *"a need to reduce perceptions of uncertainty as soon as possible to prevent the negative effects that uncertainty has on mental health"* for this group of patients.

It is therefore apparent from the existing literature that patients with atrial fibrillation have emotional needs that need to be addressed although the literature provides little insight into exactly what type of support is required. However, evidence from other conditions provides potential insight as to the type of emotional support that is needed.

Evidence from the cancer arena indicates that although patients rated emotional support from senior doctors and ward sisters as very important, such support was often not always forthcoming from healthcare professionals (Slevin et al 1996 and Krishnaysamy 1996) and it was proposed that providers needed education to enhance their skills to provide emotional support to patients (Arora et al 2007). Specific nursing interventions targeting the delivery of emotional support led to feelings of safety and security as well as indicating an improvement in sense of control (Palsson and Norberg 1995). Dakof and Taylor (1990) also found that patients with cancer reported only modest incidences of helpful emotional support from physicians with 40% of the 55 patients complaining about not receiving enough emotional support from their physicians. The evidence therefore suggests that patients with cancer would like to receive emotional support from healthcare professionals but that this was often lacking.

It is, however, important to acknowledge that the support needs of patients with cancer may differ to those of patients with atrial fibrillation due to the way cancer is socially construed. Martin et al (1994) and Masters et al (2007) compared emotional support across groups of patients with different conditions. They proposed that due to the catastrophic way in which cancer is socially constructed, the need for

emotional support may be higher for patients with cancer than those with more chronic conditions. Comparing their findings with Dakof and Taylor's (1990) work in cancer, they found there was indeed more emphasis on tangible assistance and less on emotional support for patients with more chronic conditions than their counterparts in the cancer study. The work of Masters et al (2007), Dakof and Taylor (1990) and Martin et al (1994) suggests that those people with a condition perceived to be more catastrophic would require more emotional support. Although this work compares patients across different conditions, there is some similarity with the findings from the current study where participants who report more severe AF symptoms identify a need for more emotional support.

As well as being identified as important for patients with cancer, emotional support has also been identified as key for patients with chronic long term conditions such as heart disease including heart failure and diabetes (See amongst others Moser et al 1993; Pearce et al 2013 and Sabourin and Pursley 2013). However, these studies do not distinguish differences in need depending on severity of the condition; they simply highlight a need for emotional support for people with the condition. This current study of people with AF strongly suggests that there is a greater need for emotional support with greater symptom severity which has not previously been identified in other patient groups. In this study, the need for emotional support from healthcare professionals varied across the fifteen types of emotional support investigated. Statistically significant differences were demonstrated between symptom severity (measured using the EHRA scale) and six elements of emotional support as well as an association with a further three elements. A statistically significant difference was shown to exist between symptom frequency and a need for emotional support with feeling bored and an association appeared to exist with a further six elements of emotional support and symptom frequency.

The findings of the current study indicate a need for healthcare professionals to provide emotional support for their patients with AF, in particular the group of patients reporting higher levels of symptom severity using the EHRA scale. European guidelines for the management of AF state "*Clinical evaluation should include determination of the EHRA score*" (Camm et al 2010, p.2378) and the findings from this study indicate that specific attention should be paid to the provision of emotional support for those patients scoring level IV (disabling symptoms) and

level III (severe symptoms). Symptom frequency also appeared to be linked to a higher level of need for emotional support with those patients who reported never/occasionally experiencing symptoms (using the frequency measurements proposed by Kirchhoff et al 2007) having less need for such support. Therefore, it is important that healthcare professionals consider symptom frequency as well as symptom severity when considering the need for emotional support. Clinicians working with patients with AF need to be able to identify those patients who would benefit from the provision of emotional support and either develop the skills to provide this support themselves or ensure there are referral mechanisms in place to providers of appropriate support.

Ismail and Lewin (2012) carried out qualitative interviews with patients and carers treated by BHF funded arrhythmia nurse specialists to evaluate the impact of the BHF funding and found that the specialist nurses acted as a major form of support for patients with arrhythmias, "*taking time to hear their concerns, and providing explanations and reassurance*" (Ismail and Lewin 2012, p.180) which clearly falls into the category of emotional support. This study builds on their work by recognising the importance of the provision of emotional support by healthcare professionals specifically for people with AF.

Overall the findings from this study identify the types of emotional support that people with AF would like to receive from their healthcare professionals and demonstrate the importance of providing this emotional support when people experience greater symptom severity and symptom frequency.

11.1.4 Specificity of Professional Support

The specificity of professional support has only been investigated to date in studies in considering healthcare professionals as providers of social support (which in this study would be described as professional support). Masters et al (2007), Dakof and Taylor (1990) and Martin et al (1994) all considered the specificity of social support in different patient groups and found that there were preferences for the type of support by provider. However, the healthcare providers of support in each study were limited to doctors and nurses (Dakof and Taylor 1990), doctors (Martin et al 1994) and doctors and physical therapists (Masters et al 2007). This study allowed participants to identify the healthcare provider who had been most helpful and least

helpful giving a more accurate picture of specificity of professional support for people with AF.

Informational support was the most helpful support from all healthcare providers (32 out of 78 responses) and was the most helpful support from both cardiologists and arrhythmia nurse specialists. This has close fits with the work of Masters et al (2007), Dakof and Taylor (1990) and Martin et al (1994) who all reported that informational support was identified as the most helpful type of support from the healthcare providers in their studies and highlights the importance of appropriate informational support for patients with AF.

Arrhythmia nurse specialists were also seen as key providers of emotional support for people with AF in this study. This fits with the findings from the only other study to include nurses as a provider of support (Dakof and Taylor 1990) which stated that 53% of respondents identified as emotional support as the most helpful action from nurses. In contrast, only 18% of respondents identified emotional support as the most helpful action from physicians. Martin et al (1994) reported that none of their participants described emotional support as the most helpful action from their physician and Masters et al (2007) reported that in their study this figure was only 14% of respondents. These findings indicate that nurses may be superior to doctors at providing emotional support for patients.

Given the high need for emotional support identified in this study and the fact that nurses are key providers of such support, this study supports the need for patients with AF to have access to arrhythmia nurse specialists in order to ensure they receive the emotional support they need from their healthcare professionals. However, in this study only 20 patients reported that arrhythmia nurse specialists were involved in the care of their AF opposed to 83 reporting that cardiologists were involved and 94, GPs. This suggests that a significant number of patients do not have access to nurse specialists and the associated emotional support they provide.

The picture regarding the provision of support by GPs in this study is of interest. Although they were identified as most supportive healthcare professional, they were also identified as being the least supportive. Participants reported differences in how supportive their GP was regarding the impact of their condition and their willingness to refer on for specialist care, showing variation in the professional support provided

by GPs to people with AF. Given the potential "epidemic" of AF described by Savelina and Camm (2008, p55), this study indicates that there are implications for general practice to ensure that they are supporting their patients with AF effectively.

11.1.5 Framework of professional support

Professional support is conceptualised in this study as the content of the interpersonal interaction with a healthcare professional that the person with a long term condition perceives as helpful or unhelpful, based on Schaefer et al's (1981) conceptualisation of social support. A tri-dimensional framework of professional support consisting of emotional, tangible and information components has been explored in this study to examine its relevance to the professional support needs of people with AF.

The findings from this study indicate that the tri-dimensional model of professional support is applicable to people with AF and identifies the need for specific elements of support for this group as a whole and also for different groups of people with AF.

The findings indicate needs across all people with AF including the need for informational support regarding what to do if symptoms change, tangible support regarding one healthcare professional to support people with AF with all elements of their healthcare and emotional support regarding fear of having a stroke or their condition worsening.

The findings from this study also show that the model of professional support appears to be influenced across all three types of support by symptom severity with greater need for elements of emotional, informational and tangible support identified by those with higher EHRA symptom severity score. Classification of AF also appears to influence the need for elements of informational support with people with PAF and persistent AF having greater need. Emotional support appears to be influenced by symptom frequency; people with more frequent symptoms appear to have more need for components of emotional support.

These findings have been conceptualised in a model to demonstrate the impact of variables on the need for different types of professional support and this model is shown at Figure 20. This model is in the early stages of development at present and will be refined further by post-doctoral work.

Figure 20: Model of variables influencing professional support in people with AF
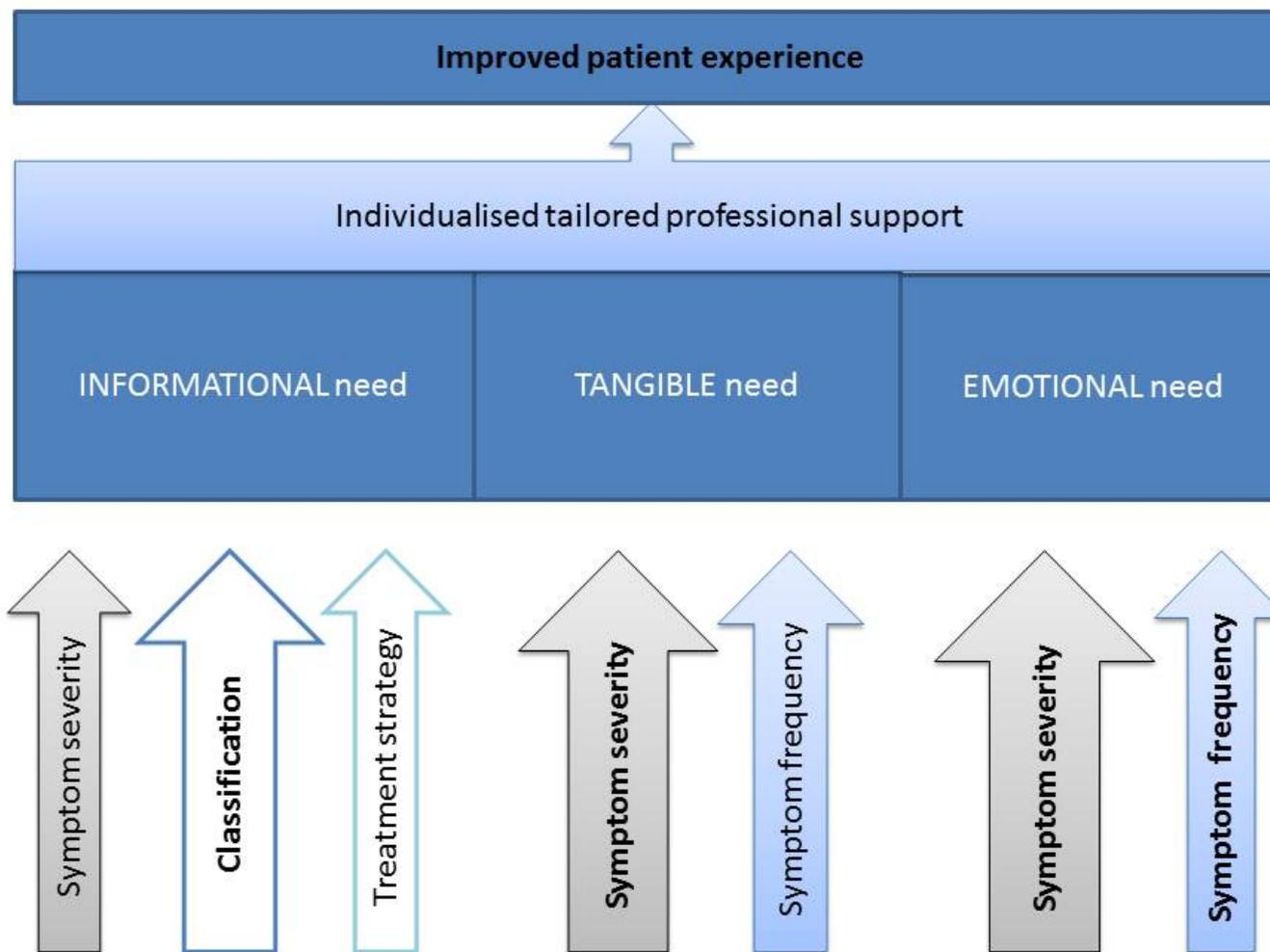
11.1.6 Summary – professional support

In summarising the findings of this study relating to the professional support needs of people with AF, the results indicate a need for healthcare professionals to provide tangible, informational and emotional support to their patients. The study has added to the existing knowledge by highlighting the importance of symptom severity on need for professional support across all three types of support. Classification and treatment strategy also appear to influence the need for informational support with symptom frequency also appearing to influence the need for emotional support. The study reinforces the work of other authors and confirmed that healthcare professionals do actually provide tangible support to their patients.

The study has also identified the specificity of professional support for patients with AF, which has particular significance with regard to the provision of emotional support. There will need to be alternative provision of emotional support for patients who do not have access to an arrhythmia nurse specialist.

In order to support an overall improvement in patient experience which has been identified as a key national priority, it is recognised that individuals have different needs and preferences for emotional, practical and informational support (NCGC 2012). This study provides a mechanism for healthcare professionals to identify those patients with AF who need professional support and also provides detail of the form that such support should take.

11.2 Physical activity and AF

The findings from this study provide a valuable insight into the beliefs regarding physical activity for people with AF and the impact of AF on their physical activity levels, an area which has not been explored to date. The aim of the qualitative interviews was to investigate professional support and as key issues specific to physical activity and exercise emerged recurrently from the interviews, items regarding this topic were included in the quantitative questionnaire to see if this was an area where people with AF needed more support from their healthcare professionals.

11.2.1 Background – physical activity

Evidence is clear that there are significant health gains from physical activity (Morris 1994 and World Health Organisation 2010) with UK Government guidance stating

physical activity should be encouraged across the population *"Engaging in physical activity has very low risks for most, but whilst the risk of poor health from inactivity is very high"* (Department of Health 2011, p.32). However, there is less evidence relating to the benefits of physical activity, exercise and AF as studies of AF and exercise have focused on the increased risk of AF in athletes and those who regularly train at high intensity (Karjalainen et al 1998; Furlanello et al 1998; Mont et al 2002; Hoogsteen et al 2004 and Graff-Iversen et al 2012).

Exercise training has been proposed as a useful adjunct in the management of patients with chronic AF given there are positive adaptations without any associated deleterious side effects (Mertens and Kavanagh 1996; Vanhees et al 2000 and Mertens 2006). A systematic review of the health benefits of exercise rehabilitation in people with AF (Giacomantonio et al 2013) identified clear benefits of moderate-intensity exercise, including improved aerobic capacity, quality of life and ability to carry out activities of daily living but highlighted there is limited research available in this field.

Given these emerging benefits of physical activity for people with AF, health professionals should be providing support and advice to people with AF. In order for this to be effective, support should be individualised and match the beliefs and experiences of individuals and their confidence about physical activity (Cavill et al 2006). Therefore, it is crucial that clinicians have an understanding of the beliefs and experiences of people with AF in order to personalise physical activity interventions appropriately and this study provides new knowledge in this field.

11.2.2 Levels of physical activity

Physical activity and exercise have been shown to have a positive effect on physical and mental health (Department of Health 2004b) and on the maintenance of functional independence so it is clearly beneficial for people with AF to remain active where possible.

Despite the multiple health gains associated with a physically active lifestyle, only 34% of adults in England (40% of men and 28% of women) meet the Chief Medical Officer's (CMO)'s recommendations for health (Department of Health 2012, p.15). In this study, only 24.1% of participants reported levels of activity that met the CMO's physical activity recommendations, indicating that people with AF are less active

than the population of England although it should be noted that the two surveys used different methods to determine levels of physical activity for their populations.

This study provides one of the first indications of the lower than average levels of activity in the population of people with AF and shows the potential for improvement in mental and physical health for this population through the provision of support to help this group achieve recommended levels of physical activity.

11.2.3 Physical activity, exercise and hobbies

The findings from the interviews indicated that people with AF were changing the amount and/or type of physical activity/exercise they participated in as a result of their AF and the questionnaire responses confirmed this finding. 73.4% of respondents reported that to some extent they had changed the amount of physical activity/exercise they do and 76.3% that they had changed the type of physical activity/exercise. There were statistically significant differences between these changes in type and/or amount of physical activity/exercise and symptom severity and between change in amount of physical activity/exercise and symptom frequency.

The majority of literature regarding physical activity and heart disease focuses on the potential benefits of activity rather than describing the impact of the condition on activity levels. This study however articulates the impact of AF and in particular symptom severity and frequency on physical activity levels and highlights the importance of symptom control to ensure that people with AF are able to achieve recommended levels of physical activity to maximise health benefits.

As well as influencing the type and amount of physical activity, symptom severity also appears to influence avoidance of travel, with those people with more disabling symptoms more likely to avoid travel in case of an episode of AF. This was clearly articulated by one of the interview participants:

"What also frightened me more than anything was if I got ill in that country" (P101).

Once again, the importance of effective symptom control is highlighted for this patient group to avoid a restriction of hobbies, work and everyday activities.

In this study, symptoms of AF have led to participants decreasing their levels of activity with an associated reduction in function. Although influencing participants in differing ways, it is clear that symptoms of AF play a significant part in the lives of participants by affecting their activities of daily living. This is in line with previous studies (Deaton et al 2003; McCabe et al 2011 and Ekblad et al 2013) and suggests that tangible support through effective symptom control to reduce functional deterioration is essential for this patient group

11.2.4 Fear avoidance beliefs

Although the fear avoidance belief questionnaire (FABQ) was developed for use with patients with low back pain (Waddell et al 1993), it has been used by some authors to assess fear avoidance beliefs in other conditions including patients with arrhythmias (Ittersum et al 2003 and Roaldsen et al 2009). Ittersum et al (2003) described that a significant number of patients with life-threatening arrhythmias fitted with an ICD reported a fear of exercise although there appear to be a wide range in FABQ scores. There was a similar range in responses to the FABQpa element of this current study; although 16 people reported a FABQpa score of 0 (indicating no fear avoidance beliefs), there was a range in the scores of the remaining 58 respondents.

Other studies investigating FABQpa and levels of activity have identified a relationship between higher FAB and lower levels of physical activity (Waddell et al 1993 and Roaldsen et al 2009) but in this study there did not appear to be a relationship between physical activity levels (calculated using the PAI) and FAB. However, this study did identify a relationship between change in hobbies and everyday activities and FAB with participants with higher FABs more likely to have changed their hobbies and everyday activities. FAB also appeared to influence avoidance of travel.

There are no previous reports of FAB and AF although there is an indication of avoidance of physical activity in the qualitative account of living with AF described by McCabe et al (2011, p.5) "*I don't dare exercise very much or I'll be - I know I'll be in a spell and then that ruins the whole day*". This has parallels to the accounts of exercise avoidance in the interview phase of this study. Williamson (2006, p.149) identifies the importance of addressing "unhelpful beliefs" as part of treatment to

avoid the "development or maintenance of disability" and therefore the findings of this study indicate the need of emotional support from healthcare professionals to identify and address fear avoidance beliefs in people with AF to ensure they are able to achieve/maintain recommended levels of physical activity.

Concluding their study of patients with arrhythmia, Ittersum et al (2003, p.121) stated that "*appropriate rehabilitation and interventions should be considered in patients with a clear fear of exercise in order to optimize their HR-QoL*". Clinically, it would be equally important to identify those people with AF who have a fear of exercise and provide appropriate support to ensure they maximise the benefits offered by physical activity and exercise. This study has shown that the physical activity component of the FABQ could potentially be a useful mechanism to identify those people with AF with a fear of exercise.

Cardiac rehabilitation (CR) programmes provide patients with CHD with a supportive environment to increase their levels of activity and therefore to help dispel any fears of the consequences of exercise (EACPR Committee for Science Guidelines 2010) and could therefore be an appropriate mechanism to provide support regarding physical activity/exercise to patients with AF. The use of CR for this patient group is reinforced by the recommendations of a recent systematic review: "*Although much further research is needed, it appears treatment strategies for AF should include cardiac rehabilitation or other supervised exercise training*" (Giacomantonio et al 2013, p.489).

The experience of the only participant in the qualitative phase of this study to be provided with specific tangible support to restore confidence in achieving previous activity levels suggests that support in the form of CR would be well received by people with AF and would provide a mechanism to address fear of exercise/physical activity in this group.

11.3 Ablation specific support

The interview phase of this study identified that people who received interventions to treat their AF had specific professional support needs. The professional support needs for people undergoing an ablation as treatment for their AF were investigated further in the quantitative phase with high support needs being identified in over 60%

in the components of informational support specific to type and amount of physical activity/exercise that could be done and when normal physical activity/exercise could be resumed.

The need for emotional support was also identified; over 40% of respondents identified high need for support specifically regarding feeling apprehensive about taking part in their usual activities/hobbies and feeling worried about whether or not the ablation would be successful.

CR programmes have been shown to be an effective method of providing support, information and advice for patients post revascularisation procedures and post ICD implantation (Department of Health 2010) and therefore could provide a mechanism to address the identified support needs for patients after an ablation for AF.

11.4 Cardiac rehabilitation for patients with AF

It is also interesting to note that the responses of participants in this study indicate that there is significant potential for health professionals to improve their provision of informational support specific to physical activity and exercise for all patients and not just those undergoing interventions to treat their AF. Over 40% of respondents in the questionnaire identified they had high need for each of the components of informational support relating to physical activity/exercise, namely how much physical activity/exercise they can do, what type of physical activity/exercise they can do and how much physical activity/exercise they should do. Additionally over 25% identified medium need for these components.

As described earlier, informational support has been identified as a priority for patients with cardiac conditions (Moser et al 1993) and the findings of this study highlight the importance of the inclusion of information regarding physical activity and exercise for people with AF. CR programmes have been shown to be an effective mechanism of providing such information and advice for patients with other cardiac conditions (Department of Health 2010) and could potentially benefit this patient group. Even when arrhythmias may prevent the use of traditional methods of setting the intensity of the exercise programme, it has been demonstrated that most patients with AF were able to participate in an exercise programme and as a result to achieve significant functional gains (Mertens and Kavanagh 1996).

It is therefore proposed that CR programmes for people with AF (not just those undergoing ablation) could therefore provide an effective mechanism to address issues identified in this study regarding people with AF, physical activity and exercise and the effect of AF on their activity levels. The experiences of participants in the qualitative phase of this study highlight the negative impact of AF on activity levels and exercise behaviours with symptoms of AF leading to a decrease in activity levels and an impact on work and other activities of daily living and the responses to the quantitative phase identify a clear need for informational support in this area. Further research is needed in this area.

11.5 Summary – physical activity

In summarising the findings of this study relating to physical activity and people with AF, the results indicate a need for professionals to provide specific physical activity support. The study added to existing knowledge by providing an insight into how AF influences physical activity behaviours of this group. Levels of physical activity in people with AF appear to be lower than the overall population, with people with AF having made changes in the amount and/or type of physical activity/exercise they undertake as a result of their condition. Hobbies and everyday activities such as work and travel also appear to be affected by their condition.

This study was the first to investigate fear avoidance beliefs in people with AF and revealed that FAB appears to have an impact on hobbies and everyday activities including travel as well as influencing amount and/or type of physical activity/exercise. Healthcare professionals will need to be able to identify those people with stronger FABs and provide appropriate support to address these beliefs.

12 Conclusion

This study sought to investigate the professional support needs of people with AF using a theoretical framework developed from the social support literature. The findings have built on the limited amount of literature regarding professional support and added new knowledge in this field specific to people with AF as well as in developing knowledge and understanding in the area of physical activity and AF. This concluding chapter summarises this contribution to knowledge as well as highlighting the implications for clinical practice, policy and future research. Dissemination of the findings will also be discussed.

12.1 Contribution to new knowledge

The discussion chapter has highlighted areas that have contributed to new knowledge; these are now summarised in this section.

12.1.1 Professional Support for people with AF

This study proposed a framework for professional support that was built on the social support literature. Three dimensions of professional support were identified and explored in more detail to ascertain specific components of support for people with AF. As well as describing specific components of professional support needed by people with AF, the study revealed that different groups of people with AF may need more support.

The study determined the importance of symptom severity of influencing need for professional support across all three types of support. Additionally the study is highly suggestive that classification influenced the need for informational support: people with PAF or persistent AF had higher need for informational support from their healthcare professionals regarding how to manage their AF at home and what to do if their symptoms changed. Symptom frequency also influenced the need for emotional support, with those experiencing intermediate or frequent symptoms (as defined by Kirchhof et al 2007) needing more emotional support from their healthcare professionals.

The study also reinforced the work of other authors (Dakof and Taylor 1990; Martin et al 1994; Miles et al 1999; Koivula et al 2002; Warwick et al 2004 and Masters et al 2007) in confirming that healthcare professionals do actually provide tangible support

to their patients in the form of medical care. A specific example of tangible support identified in this study was the support that one professional provided through the coordination of healthcare for people with AF.

12.1.2 Physical activity

The study provided new knowledge by offering an understanding into how AF influences physical activity behaviours of this group. Levels of physical activity in people with AF appear to be lower than the overall population, with people with AF having made changes in the amount and/or type of physical activity/exercise they undertake as a result of their condition. Hobbies and everyday activities such as work and travel also appear to be affected by their condition.

This study was the first to investigate fear avoidance beliefs in people with AF and revealed that FAB appears to have an impact on hobbies and everyday activities including travel as well as influencing amount and/or type of physical activity/exercise. This suggests that healthcare professionals will need to be able to identify those people with stronger FABs and provide appropriate support to address these beliefs.

The study is also highly suggestive of the need for professionals to provide specific physical activity support to people with AF as the findings from both the interviews and questionnaires indicated that this was lacking for most participants. People who undergo ablation as part of treatment for AF have specific informational and emotional support needs specific to resuming physical activity.

12.2 Implications for clinical practice

In light of the findings from this study, there are clear implications for clinical practice regarding both professional support for people with AF and physical activity.

12.2.1 Professional support implications for clinical practice

The study highlights the influence of symptom severity on the need for professional support for people with AF and therefore indicates the importance of accurate assessment of symptom severity and that this is documented for all patients with AF. European guidelines for the management of AF state "*Clinical evaluation should include determination of the EHRA score*" (Camm et al 2010, p.2378) and the findings from this study indicate that this should form an integral part of the clinical

assessment of patients with AF in order to identify their potential need for professional support.

The study indicates a need for healthcare professionals to provide emotional support for their patients with AF, in particular the group of patients reporting higher levels of symptom severity using the EHRA scale. The findings suggest that specific attention should be paid to the provision of emotional support for those patients scoring level IV (disabling symptoms) and level III (severe symptoms). As highlighted earlier, specialist nurses may be best placed to identify the need for such support and either deliver the support themselves or refer on to other professionals as part of their overall coordination of care role.

The provision of informational support regarding how to manage AF at home and what to do if they get an episode of AF appears important for patients with PAF/persistent AF and the findings suggest that clear guidance in these areas should be provided for patients with these classifications of AF. The traffic light approach as used for patients with heart failure (Greater Manchester Collaboration for Leadership in Applied Health Research and Care, no date) could be an effective method of addressing this need for these specific types of informational support as it provides clear instructions depending on the patient's changing symptoms.

There also appeared to be an association between treatment strategy and informational support regarding what to do if their symptoms change. Participants with rate treatment strategy tended to have medium to high need for this type of informational support, whereas those with a rhythm treatment strategy tended to have a more even spread of need. As detailed above, the traffic light approach could provide a mechanism to deliver this support.

This study was highly suggestive that symptom severity influenced the need for tangible support in patients with AF; those participants with higher symptom severity having higher need for support in three components of tangible support. The findings support the need for symptom severity to form part of the clinical assessment to identify those patients who may need more tangible support.

Camm et al (2010) describe how AF tends to progress from PAF through to persistent AF and eventually onto permanent AF and therefore assessment of

symptom severity, symptom frequency and professional support needs would need to be repeated on an ongoing basis throughout the patient's care and management to ensure that appropriate professional support is provided to help them manage their condition and to optimise their experience of care.

12.2.2 Physical activity implications for clinical practice

In addition to the professional support implications for clinical practice that have been identified in this study, there are implications for clinical practice specific to physical activity.

This study identifies the potential impact of symptom severity and frequency on physical activity levels of people with AF and highlights the importance of symptom control to ensure that people with AF are able to achieve recommended levels of physical activity to maximise health benefits. The study supports the need for optimal symptom control to therefore be a goal for treatment for this patient group. However, given that treatment success is variable and PAF and persistent AF have a pronounced tendency to recur (Fuster et al, 2006) it is also important that healthcare professionals provide ongoing effective support to people with AF to encourage physical activity/exercise.

The influence of fear avoidance beliefs in people with AF on physical activity/exercise, hobbies and everyday activities identified in this study supports the need for healthcare professionals to be able to identify those people with stronger FABs and provide appropriate support to address these beliefs. The FABQpa used in this study which was specifically adapted for people with AF may provide an appropriate tool to identify those people with AF who have stronger FABs and therefore need more support.

Based on the findings of this study, there are well-defined implications for clinical practice for those healthcare professionals working with people with AF. However, it is important to recognise that the populations for both phases of this study were open to potential selection bias due to the recruitment processes and therefore further research should be undertaken to confirm these findings across the wider population of people with AF.

12.3 Implications for future research

In order to further develop knowledge and understanding regarding the professional support needs of people with AF, there is a need for additional research into the tri-dimensional model of professional support developed in this study. Further research should establish whether there are any additional components of each type of support that need to be included in the framework. Additionally further investigation into the proposed model of professional support for people with AF and the influences of symptom severity, symptom frequency, classification and treatment strategy on need could provide more specific guidance that would be able to inform clinical practice, through the identification of those groups of people with AF who are in most need for support from their healthcare professionals. More investigation is required to test the validity and reliability of the questionnaire as an assessment tool to identify professional support needs for people with AF.

In the same manner, there is a need for further research to confirm the physical activity/exercise findings of this study. There is a need for further investigation into the use of the FABQpa for people with AF to confirm its suitability for people with AF as well as investigating the potential for cardiac rehabilitation programmes to provide the required support for this patient group. Given the varied clinical presentation of people with AF, it may be most relevant to consider investigating the potential of cardiac rehabilitation to address the support needs of patients after ablation. This study indicated a clear need for support for people with AF undergoing ablation to receive professional support after their intervention and as this has a close fit with those people who already receive cardiac rehabilitation after other cardiac interventions, this could be an easily defined group in which to investigate benefits before considering the wider group of people with AF.

Despite the limitations, the findings from this study provide an indication of the professional support needs and physical activity behaviours of people with AF which has not previously been described. Further research is required however to confirm these findings across the wider population of people with AF.

12.4 Implications for policy

Support from healthcare professionals for patients with long term conditions such as AF has been identified as a priority in policy documents (Department of Health,

2004); this study shows that it is important to identify the type of professional support and its associated components to ensure such support is effective and personalised to each individual. The study also supports the need for one healthcare professional to provide support to people with AF regarding all aspects of their condition; a role outlined in the arrhythmia chapter of the CHD NSF as a named arrhythmia care coordinator (Department of Health 2005a). Initial ACC posts were funded through BHF awards and this study reinforces the findings of the evaluation from those awards (Ismail and Lewin 2010) that the ACCs are effective at providing such support. This study is highly suggestive that these roles should be extended to ensure that all people with AF have access to such support, which has clear resource implications regarding the commissioning and delivery of such services.

The effective provision of professional support for people with AF will have a clear impact on improving their experience of care. Guidance specific to improving patient experience (NICE 2012a, NICE 2012b and NCGC 2012) highlights the importance of providing tailored support for individuals that meets their identified needs; the use of the professional support framework developed in this study can help identify support needs, ensuring that people have individualised professional support and therefore leading to an overall improvement in patient experience.

12.5 Dissemination of the study findings

Dissemination of the findings of research has been identified as a central part of the research process (Locke et al 2000). Several approaches to dissemination are planned for this study, with some already undertaken. Polit and Beck (2006) highlight that conference presentations and publication via journals are two commonly utilised strategies to disseminate findings.

The findings from the qualitative interviews have already been presented at two international conferences and submitted for publication through appropriate journals. (See Appendices A5, A7 and A10 for details of poster presentations to Heart Rhythm Congress and the European Society of Cardiology's 11th Annual Spring Meeting on Cardiovascular Nursing and draft journal article)

In order to share the findings of the study with participants, specific dissemination strategies have been adopted. Interview participants were asked if they would like to

receive a summary of the findings from the interviews and those who did were sent a copy of the poster presentation to European Society of Cardiology's 11th Annual Spring Meeting on Cardiovascular Nursing (Appendix A7) to inform them of the findings.

As part of the recruitment process for the quantitative phase of the study, it was agreed that the findings will be shared with the wider AFA membership. Now that the dissertation has been produced, discussions will take place with the AFA to agree the most appropriate way to share findings with their membership, including those who participated in the questionnaire.

Further papers will developed to share the findings of the overall study with the wider professional and academic community to share knowledge and understanding developed in this study and to facilitate further research and changes in clinical practice.

12.6 Final remarks

The initial motivation for this study arose from the belief that people with AF were not having the best experience of care in the NHS and a desire to identify how to improve treatment and care to rectify this situation. Having listened to the experiences of interview participants and read the responses from the questionnaires, it was apparent that there is a need to ensure that personalised professional support is available to all people with AF to support them through the "emotional rollercoaster" of their condition.

Although there has been significant emphasis in the existing literature on the medical and therapeutic management of AF, there is very little research that illustrates what it is actually like to live with AF every day. This research study does describe the experience of people with AF and the challenges that living with this condition brings. It exclusively shows that people with AF need more support from their healthcare professionals to manage these challenges. Additionally, the findings of this study depict what this support looks like in detail providing healthcare professionals with unique knowledge as to the types of support they should consider providing for people with AF as well as how this support may vary in different groups of people with AF. This study also provides healthcare professionals with a tool to assess and

measure the types of support required by patients with AF, ensuring patients receive the support they need to manage their condition.

The experiences detailed in this research have informed the development of an emerging model of professional support for people with AF and helped to identify groups of people with AF who may need different types of support from healthcare professionals. By identifying and delivering the professional support our patients need, we as healthcare professionals can ensure they have the best possible experience of care.

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