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Patients' experiences of atrial fibrillation and comorbidity management in clinical practice: a pan-European qualitative descriptive interview study

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ABSTRACT

Objective The objective is to explore patients' perceptions on the management of atrial fibrillation (AF) and associated comorbidities.

Design A descriptive qualitative study involving in-depth individual interviews, analysed using Braun and Clarke's approach to Reflexive Thematic Analysis.

Setting Cardiology departments in teaching hospitals in five geographically diverse European countries—Belgium, Greece, Poland, Spain and the Netherlands.

Participants 30 adults aged 65 years or older, diagnosed with AF, with two or more confirmed comorbidities were interviewed.

Results The average age was 73 years, 37% were women and the most common comorbidity was hypertension (n=26, 87%), followed by hypercholesterolaemia (n=12, 40%), obesity (n=10, 33%), hypothyroidism (n=9, 30%) and diabetes (n=7, 23%). Three main themes were identified: (1) navigating the diagnosis path and adapting to life with AF, (2) normalising symptoms and treatment burden and (3) striving to build a therapeutic relationship.

Respondents had some knowledge about the relationship between comorbidities and AF but lacked understanding of how these comorbidities related to AF. Participants raised concerns regarding their medications, especially anticoagulants, with a desire to be given more information about them. Participants were motivated to make lifestyle adjustments but reported a lack of education and advice on how to implement and maintain these lifestyle changes. Overall, participants were very satisfied with their cardiology/AF teams, and they emphasised the importance of a person-centred approach. There was a perceived disjointedness to healthcare systems, with some reporting multiple appointments at different locations, leading to participants being frustrated and highlighting the lack of integrated care.

Conclusions In-depth interviews provided an excellent platform to explore the perceptions and experiences of patients living with AF and associated comorbidities and highlighted the lack of an integrated approach to multimorbid AF management.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ In-depth qualitative individual interviews with 30 patients from five European countries were undertaken who commented on issues from the time of diagnosis to navigating treatment and healthcare systems.

⇒ The interviews provided patients the opportunity to outline their perspectives on the current clinical practice of atrial fibrillation management in terms of what worked well and what could be done to improve services.

⇒ Although patients from five European countries were interviewed, the themes identified may not be applicable to patients in other geographical locations.

⇒ Participants were identified through cardiology departments in teaching hospitals and may not be representative of patients in primary care.

INTRODUCTION

As the most common arrhythmia, atrial fibrillation (AF) places significant burdens at the individual, population levels and on healthcare systems. The 2019 global burden of AF was estimated at 59.7 million,[1] and this is likely to continue to grow with ageing populations and people living longer with chronic conditions. Multimorbidity is defined as a patient diagnosed with two or more concomitant conditions, and the known AF comorbidities include hypertension, sleep apnoea, diabetes and coronary heart disease, for example.[2 3] Given the increasing prevalence of AF and increased all-cause mortality in those with associated comorbidities, there is a need to optimise integrated care using pathway-based interventions to ensure a standardised evidence-based approach.[4] Structured pathway-based interventions are tailored to AF management to enhance application of the various aspects of AF care, including management of AF-associated conditions and risk factors. However, there is a paucity of information on how comorbidities are managed and how integrated care is implemented.[5] A systematic review reported that the benefits of integrated care for AF include reduced cardiovascular hospitalisations and all-cause mortality.[6] However, the authors concluded that to deliver integrated care in AF, the optimal settings need to be identified along with appropriate methods and components. The issue of managing comorbidity in AF is gaining attention in terms of how comprehensive multimorbidity can be implemented into practice.[7 8] As such, the European Heart Rhythm Association (EHRA)-PATHS—*Addressing multimorbidity in elderly atrial fibrillation patients through interdisciplinary, tailored, patient-centred care pathways* project—aims to develop a new pathway of care for older patients (≥65 years) with multimorbid AF through interdisciplinary, patient-centred and systematic approaches. It is a Horizon 2020 project coordinated by the EHRA and the European Society of Cardiology (ESC), with 14 research collaborators from across Europe. As part of the project, a survey was undertaken among 339 clinicians across Europe to identify current clinical practices, which revealed a lack of integrated care models, organisational and structural barriers and issues with patient adherence.[9] This lack of an integrated approach means that often patients are not referred for other conditions and do not benefit from optimal specialist care for concomitant illnesses. The need for systematic integrated management of AF-related comorbidities was evident from the survey. To complement the healthcare professionals' experiences, a second component of the work package was to undertake qualitative interviews with AF patients across Europe. By mapping current practice and identifying issues in AF and comorbidity, management from clinicians' and patients' perspectives will allow the EHRA-PATHS investigators to develop new care pathways to detect, tackle and follow up on multimorbidity and polypharmacy in elderly AF patients using an integrated, multidisciplinary and patient-centred approach and then to evaluate the benefits of these new pathways. The primary aim was to explore patients' perceptions on the management of AF and associated comorbidities using a qualitative approach.

To achieve this, the following objectives were met:

1. Explore the patients' experience of living with AF and associated comorbidities and how it is managed in clinical practice (ie, their lived experience).
2. Explore patient perceptions of specific components of AF care.
3. Determine patients' perceptions on the evidence of integrated care and shared decision-making in clinician consultations.
4. Describe the challenges reported by patients relating to their current AF treatment (especially in medication and polypharmacy).
5. Provide patients the opportunity to inform optimisation of AF management and offer suggestions on how the service could be improved.

METHODS

Design and setting

This descriptive qualitative study using in-depth interviews was completed, and this manuscript has been developed following the Standards for Reporting Qualitative guidelines.[10] A constructive approach was undertaken, which allows participants with similar conditions (in this case, AF) to actively construct their own understanding of AF and associated comorbidities through their experiences and interactions with AF and comorbidities in terms of living with these conditions and managing symptoms.[11] This qualitative framework values participants' expert knowledge, and this can, in turn, lead to informing and improving clinical practice.[12] The study was undertaken in five geographically diverse countries within Europe, including Belgium, Greece, Poland, Spain and the Netherlands. One research site was selected within each participating country. The rationale for this approach was to attempt to capture patient perspectives from across Europe. The sites were academic cardiology departments within university hospitals. These countries were selected using pragmatic methods applying self-selection based on the availability and interest of local primary investigators within the EHRA-PATHS working group.[9]

Study sample and recruitment

Between December 2022 and February 2023, following consent, in-depth interviews were conducted with 30 participants who were established multimorbid AF patients within the participating hospital sites (ie, urban locations). A pragmatic decision was made in relation to sample size, where each site would aim to recruit 5–6 participants (total sample of 30 participants) rather than following data saturation theory.[13] Potential patient participants were identified by their clinical team but were recruited by a member of the local research team, where informed consent was taken. Patients were purposively selected at each site according to the eligibility criteria, and therefore only those who had received or were receiving treatment by a cardiologist were eligible. To achieve a maximum variation sample, the central research team maintained a sampling framework considering factors such as participant age, type and number of comorbidities.

Eligibility criteria

The inclusion criteria for potential participants were those aged 65 years or older, diagnosed with AF, have two or more confirmed comorbidities, be under the care of a cardiologist for treatment of chronic AF, be established on required treatment, clinically stable at the point of recruitment, able to give informed consent and speak the local language of the research site. Those who were deemed clinically unstable at the time of recruitment, were awaiting acute management relating to either AF or associated comorbidities, had long-term psychiatric problems/moderate cognitive impairment (ie, dementia) or were unable or unwilling to consent were excluded.

Data collection

Interviews were conducted by a member of the local research team who was an experienced clinician or an experienced researcher (Belgium) who had undertaken training in how to conduct interviews for qualitative research led by the chief investigator. Interviews at four sites were undertaken by one person, while two clinicians undertook the interviews in Spain. Interviews were conducted face to face at each site within the hospital site (in a private room) or via an online MS Teams call. Patients who agreed to participate were interviewed by a member of the local research team in the local language of the patient. These interviews were recorded, transcribed, anonymised and finally translated into English.

The semistructured interview guide was developed by the EHRA-PATHS consortium using the literature on qualitative interviewing techniques and the existing evidence on multimorbid AF. The questioning approach was open-ended, and participants were encouraged to lead the discussion. The final topic guide was reviewed and approved by the consortium and patients' advisory board.

Patient and public involvement

Two patients with AF were part of the EHRA-PATHS patient advisory board and reviewed the proposed interview questions. They provided feedback including the first question about other medical conditions and suggested the question about asking participants about one positive experience and one preventable experience (as opposed to a question on facilitators and barriers to AF management). These changes were made to the questions and approved by them (as part of the patients' advisory board) and the consortium. The results from the interviews were also presented to the patients and they provided comments on the findings. A joint conference presentation was also undertaken that provided one of the patient advisors to comment on the findings from his perspective as a patient with AF and discuss the implications of the findings. The interview schedule was as follows:

1. What medical conditions aside from AF do you suffer from (think about conditions for which you see your doctor regularly or for which you take regular medication, for example, diabetes, hypertension)?
2. What was your experience of the process by which you were diagnosed with AF in the first place? How might this be improved?
3. What were your experiences of how your condition was treated, including lifestyle measures, medication or hospital treatments? Are there any additional resources that might have helped you feel more secure in living with, and managing the condition?
4. In terms of your treatment, did you feel fully informed about the decision-making process? How might your own experience of deciding on different treatment options be improved?
5. What were your experiences of your interactions with healthcare professionals? Is there any one person in the team you found particularly helpful?
6. Tell us one positive experience delivered by your healthcare professionals which you would most like all patients with your condition to have access to, and one preventable experience which you would most like us to ensure patients avoid.

Rigour

Rigour and trustworthiness were maintained in the study through internal monitoring against a trustworthiness criterion, which demonstrated that data collection followed a precise, consistent and exhaustive approach.[14] The translated transcripts were sent back to the interviewers at each site to check for accuracy and to ensure the integrity of the translation. The findings were guided by the 'MIRACLE' narrative framework that emphasises the importance of meaningful, interpretative, relational, authentic, contextualised, linked and emic narratives to ensure meaningful descriptions in qualitative research.[15 16]

Data analysis

Data analysis was undertaken using Braun and Clarke's process of reflexive thematic coding and took the key characteristics into account that include theoretical flexibility from a constructionist paradigm, critical reflection from the researchers and applying a meaning-based pattern with the themes.[17 18] Interviews were undertaken in the participants' local language and then translated into English by the local research team at each location. The translated transcripts were uploaded to NVivo V.11 (QSR International) and initial data analysis was undertaken by GL. This was followed by secondary coding by a second author (EB). The principal steps of analysis were performed: becoming familiar with the data (reading and re-reading transcripts), generating initial codes, constructing themes, reviewing themes, defining and naming themes and then writing up the findings. Themes and subthemes, including definitions, were agreed through a process of discussion between coders and reviewed by the researchers who had conducted the interviews to ensure rigour. Themes and subthemes are reported in the results section and are illustrated using verbatim quotes and a pseudonym for the participant and the number of comorbidities.[17]

RESULTS

Across five countries (Belgium, Greece, the Netherlands, Poland and Spain), a total of 30 patients were interviewed. The mean age of participants was 73 years (range 65–84 years) with 19 men and 11 women (table 1). The duration of the interviews was between 15 and 60 min, which were participant driven.

In terms of number of comorbidities, nearly 40% of participants (n=11) had three comorbidities and 43% had four or more comorbidities (n=13) with hypertension

Table 1 Characteristics of participants, number and type of comorbidity

Characteristics	Frequency (n, %)
Mean age	73 (65–84)
Gender	
Male	19 (63%)
Female	11 (37%)
Number of comorbidities	
2	6 (20%)
3	11 (37%)
4	6 (20%)
5	4 (13%)
6	2 (7%)
7	1 (3%)

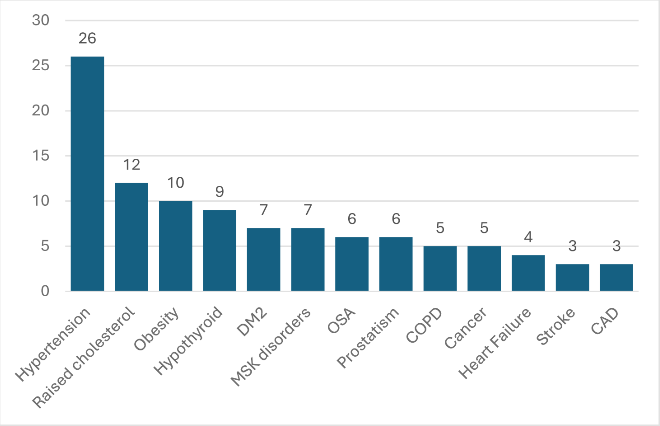

Figure 1 Frequency of comorbidities in patients. CAD, coronary artery disease; COPD, chronic obstructive pulmonary disease; DM2, diabetes mellitus type 2; MSK, musculoskeletal; OSA, obstructive sleep apnoea.

being the prevalent condition (n=26, 87%), followed by hyperlipidaemia (n=12, 40%) (figure 1).

Thematic analysis of the interviews revealed the following three themes about living with AF and associated comorbidities from the time of diagnosis to navigating treatment and the healthcare system: (1) navigating the diagnosis path and adapting to life with AF, (2) normalising symptoms and treatment burden and (3) striving to build a therapeutic relationship (figure 2).

Theme 1: navigating the diagnosis path and adapting to life with AF

Participants described their experience in terms of how long it took to obtain a diagnosis, with some reporting symptoms over several years before receiving a diagnosis.

> I thought the doctors knew what they were doing. I trusted the doctors. The only thing that bothered me was that I waited 2 years from the diagnosis to be admitted to the referral center for further diagnostics, after consultations with a cardiologist…. A pulmonologist and a cardiologist who take care of me constantly. I have visits every 3-4 months. [Female, Poland, 4 comorbidities]

The non-standardised approach to AF diagnosis was also noted:

> He then had me do a Holter test. Hanging on a box like that for 24 hours and so it showed I had an irregular sinus. [Male, Belgium, 3 comorbidities]
>
> 5 years ago, I felt palpitations in my chest at rest. At first it was once a day and after that every few days. Then more and more often. Holter ECG tests performed two times showed nothing. One day I was walking down the street and I felt discomfort again. I was passing the clinic - I asked for an ECG test, which confirmed an episode of atrial fibrillation.' [Female, Poland, 4 comorbidities]

Theme 2: normalising symptoms and treatment burden

This theme highlighted the symptom and treatment burden that people with AF experience in their daily lives, with four issues identified: (1) physical impact of symptoms, (2) knowledge about prescribed medications, (3) interventions and symptom relief and (4) the need for greater education and advice.

The physical impact of AF symptoms was evident:

> The arrhythmia complaints were terrible and unpleasant. [Male, Poland, 8 comorbidities]

The symptoms sometimes resulted in patients having to attend the emergency department.

> In the sense that during a fairly acute episode of that atrial fibrillation, I ended up at the emergency department. [Male, Belgium, 6 comorbidities]

Symptoms were also perceived as quite frightening:

> I felt scared because of the unpleasant situation I was facing until the AF episode ended. [Female, Greece, 3 comorbidities]

Knowledge about prescribed medications was identified, with some participants unsure of why certain medications were prescribed. Some commented on not receiving adequate information about their medications.

> Well, I don't know what I can do my medications, but for what? Yes, I know I have a blood thinner, but I don't believe for heart fibrillation. [Male, Netherlands, 4 comorbidities]
>
> Well, at least informing the patient what each thing is for, because normally they send you the medicines and they don't tell you why, then they change them, I had the omeprazole, they change it for another, they add that almagato [Antacid] and they don't tell me why. [Male, Spain, 4 comorbidities]

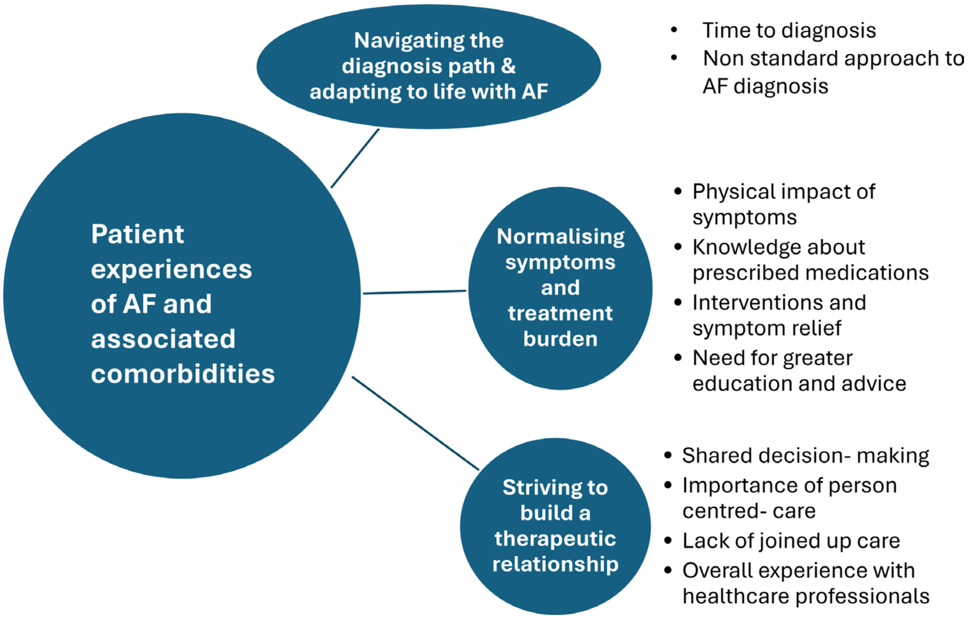

Figure 2 Thematic analysis of patient experiences of atrial fibrillation (AF) and associated comorbidities.

However, some participants highlighted how education improved their adherence once they understood why they were prescribed it:

> My positive experience was the changes in medication because there was a problem of understanding and taking them properly. [Male, Greece, 2 comorbidities]

In relation to interventions, participants commented on undergoing cardioversion and the immediate relief associated with it (in terms of symptoms):

> Yes, that cardioversion was I think in the month of June I think. Now I did feel better at that time. [Male, Belgium, 3 comorbidities]
>
> I hope I'm satisfied with the cardioversion. I am very satisfied with my GP as well. There is no other way. [Female, Netherlands, 4 comorbidities]

Participants had undergone more than one cardioversion, highlighting the need for more than one intervention to treat AF symptoms:

> I have about a period of a few years back and people were not immediately enthusiastic, and neither was I actually. But anyway in the end, I'm going to have had cardioversion there once or three times, yes, really, but twice that I had been, that it was over then, spontaneously disappeared therefore, in the end the cardioversion did not help, and then referred again. [Male, Netherlands, 3 comorbidities]
>
> I needed hospitalization once and it is clearly not the most pleasant experience. The next few times I did cardioversion at home by myself with medication and the next day I went for an examination and consulted with my cardiologist. [Female, Greece, 3 comorbidities]

The need for further education and advice on lifestyle-related risk factors was also seen.

> Yes, because initially the cardiologist was of the opinion that maybe I didn't really need to do that rehabilitation, but yes, who am I to know if I'm doing well or not? And that was so bit yes you think you're doing well but you don't actually know. You think those are exercises and then I think especially the exercises really focused on cardio. [Male, Belgium, 3 comorbidities]
>
> I did it wrong - I limited my physical activity. I didn’t have advice on what I could do so that I can stay fit. [Female, Poland, 8 comorbidities]

Others, however, reported their frustration about how information is conveyed and the need for non-technical language:

> There was full information from our doctor. I wish he used simpler terms though. [Male, Greece, 2 comorbidities]

Theme 3: striving to build a therapeutic relationship

This theme emphasised the interaction between healthcare professionals and patients and issues with current clinical practice, especially around shared decision-making and person-centred care:

> I always received information and instructions. All the decisions I made were right and I was well prepared for the procedures I had. [Male, Poland, 5 comorbidities]

Person-centred care was also seen in the comments from patients in their interactions with healthcare professionals:

> I think so, I have no impediment to say that they have not treated me or left me without doing anything for too long, but they have informed me of everything and I have been able to participate in my treatment, they have made me feel part of this process and I have understood everything that way that in that aspect well. [Male, Spain, 3 comorbidities]

The lack of joined-up care was reported as participants described appointments with different specialists and suggested that there is poor or a lack of communication between specialists from their perspective:

> Yes, you can't intervene, if you don't know or if you don't report it. [Female, Belgium, 5 comorbidities]

> Yes, they told me that I had and that they were going to do it, yes, but that I have to be doing everything in each hospital, (Hosp A, Hosp B) bothers to me. It could be better informed, yes, because they do each thing, medication, exams and they don't always explain well what they are for, and even less do they organize it so that it is comfortable for the patient because they give you appointments on different days, different times and different places. [Male, Spain, 4 comorbidities]

The overall experience with healthcare professionals, including physicians and nurses, was also highlighted.

> All the doctors were able to make it all clear to me in human language, what message that they wanted to bring.…I actually got that nicely drawn and explained. [Male, Belgium, 3 comorbidities]

> I am happy overall with the treatment I had, and I think that everyone is doing their best. A helpful person was my cardiologist. [Female, Greece, 3 comorbidities]

Critically, one participant commented on the AF specialist nurses:

> You also have those nurses there who are now somewhat specialized in that and are easier to access. [Female, Belgium, 5 comorbidities]

DISCUSSION

To the best of our knowledge, this is the first qualitative study interviewing older patients from several European countries about their experience in relation to AF and associated comorbidities. The in-depth interviews provided participants with an opportunity to talk about their experiences in relation to their AF and comorbidities and provide their unique perspectives. The results highlighted the burden associated with AF in terms of symptoms and treatment while also showing the importance of shared decision-making and person-centred care as part of the therapeutic relationship. It confirmed and extended on earlier self-reported questionnaire-based findings.[19] Several themes emerged, including the lack of integrated care, the need to attend multiple appointments and their desire for more information and education about their lifestyle-related risk factors. A recent study highlighted differences between physician and patient-reported health status, with physicians' under/over estimation of health status, which reinforces the importance of undertaking qualitative research that allows patients to articulate their issues in relation to AF and comorbidity management and provide their lived experience of long-term chronic issues.[20]

Medication adherence and adverse events are commonly reported in AF in the context of direct oral anticoagulant treatment, which forms the cornerstone of stroke prevention. Several participants commented on their medication, gaps in their knowledge and the need for further education. In-depth interviews with 56 patients noted the inadequate education and follow-up.[21] Many patients were worried about the risk of stroke and understood the importance of taking their blood thinners, but from some of the quotes, it was clear that further information was needed to improve their understanding of the medications. One important point from the literature and our interviews is the need for relatively regular reviews and giving patients opportunities to ask questions. Retention of information is limited and suggests the need for regular consultations with the healthcare team, as well as providing educational material in various forms.[21 22]

A specific question was asked about shared decision-making, as there is evidence to support its benefits in AF management.[23] The majority of patients reported positive interactions with their cardiologists and were satisfied with the decisions about their treatment. However, this must be considered within the scope of their need for further education and advice about how to modify their lifestyles, especially in relation to physical activity. Many believed they already had a good diet, but this is their perception, and it would be interesting to undertake formal reviews of their diets in terms of saturated fat intake, alcohol intake and consumption of fruit and vegetables. Others have noted limited involvement of their patients in decision-making about anticoagulation medication and the need for patients to feel supported and highlighted, once again, the importance of specialised MDT (multidisciplinary team) care for patients with AF.[23–25]

Making changes to lifestyle is complex and requires behaviour change and motivation from the patient as well as the knowledge and skills to do so, usually provided by healthcare professionals.[26]

As patients often have multiple comorbidities, they struggle to manage these, as seen in our interviews. Undoubtedly, having an integrated system for AF management that allows for a multidisciplinary approach would be useful. Often, clinicians do not have the expertise in health behaviour change techniques, so it would be essential to ensure that the healthcare professionals are better equipped to implement behaviour change for modifiable risk factors.

The importance of person-centred care was also viewed as important by several participants, and we know from other cardiac conditions such as coronary disease and heart failure that a person-centred approach improves patient experience and ensures patients feel included in decision-making.[27 28] The patients' perceptions of AF comorbid management confirmed the findings from the clinician survey, which also highlighted the lack of integrated models of care, patient adherence issues and treatment-related adverse events.[9] A recent state-of-the-art paper, where the relationship between AF burden and outcomes was explored, concluded that therapeutic burden should be a therapeutic goal.[29] This confirms the themes that were recorded in our interviews, where participants expressed issues with several issues in relation to their AF and associated comorbidities. It is clear that improving access to lifestyle and health promotion interventions is a priority for both patients and clinicians, as well as the need for structural changes to enable an integrated system to perform effectively. The need for greater interdisciplinary working between primary care and secondary care was also evident, and this has been highlighted previously.[30 31]

These interviews support the need for clinicians to ensure discussions and advice on risk factor management are part of their consultation and also to offer patients an opportunity to discuss their issues and concerns in relation to symptoms and treatment burden. The latest ESC guidelines for AF acknowledge the importance of comorbidities in AF and state that comorbidities and risk factors must be managed early to optimise treatment and improve outcomes.[32] The 2024 guidelines propose a multidisciplinary approach to AF management and emphasises active patient engagement and a patient-centred holistic approach using a new framework: AF-CARE (C—Comorbidity and risk factor management, A—Avoid stroke and thromboembolism, R—Reduce symptoms and E—Evaluation and dynamic reassessment). Implementation advice includes shared decision-making and patient education and empowerment with an emphasis on self-care.

Limitations

There are some limitations to the study that need to be acknowledged. Due to time and financial constraints, it was not possible to include multiple European countries, and therefore the results from five, although geographically diverse countries, may not be representative of other European countries. Participants were identified from cardiology services that were hospital based, and recruiting participants from primary care may have highlighted other themes. Interviews were undertaken in the respective local languages, and therefore patients who were not fluent in the local languages were not eligible. However, by undertaking interviews in the local language, we believe we provided participants with the best opportunity to express themselves.

CONCLUSION

Patients confirmed to us, in their own words, the perceived complexity of AF management and associated conditions. AF management requires structured, integrated care with a need for interprofessional working to improve their outcomes and ensure that they are managed in a timely and efficient manner.

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Contributors HH conceived the overall study. GL and EB designed the qualitative component, RO, BAM, RD, ST, SK, MJ-A and DEM undertook the interviews. GL and EB undertook the initial analysis and reviewed by RO, BAM, ST, SK, MJ-A and DEM. All authors contributed to the writing of the manuscript and approved the final version. GL is the guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, conduct, and reporting of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants. Centrally ethical approval for this study was given by King's College London after proportionate review (ref: LRS/DP-21/22-26952) and each participating site gained ethical approval locally to ensure that the ethical and legal requirements of each site and country were met. Data collection did not commence until after these requirements were fully met. Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

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