

# Patients' experiences of atrial fibrillation and non-vitamin K antagonist oral anticoagulants (NOACs), and their educational needs:

Clarkesmith, Danielle; Lip, Gregory; Lane, Deirdre

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**Patients' Experiences of Atrial Fibrillation and Non-Vitamin K Antagonist Oral Anticoagulants  
(NOACs), and their Educational Needs: A Qualitative Study**

Danielle E Clarkesmith<sup>1</sup>

Gregory Y H Lip<sup>1,2</sup>

Deirdre A Lane<sup>1,2\*</sup>

<sup>1</sup>University of Birmingham Institute of Cardiovascular Sciences, City Hospital, Sandwell and West  
Birmingham Hospitals NHS Trust, Dudley Road, Birmingham, B18 7QH, United Kingdom

<sup>2</sup> Aalborg Thrombosis Research Unit, Department of Clinical Medicine Aalborg University, Aalborg,  
Denmark

**Short title:** Living with atrial fibrillation and taking NOACs

**\*Corresponding Author:**

E-mail: [d.a.lane@bham.ac.uk](mailto:d.a.lane@bham.ac.uk) (DAL)

## **ABSTRACT**

**Purpose:** Qualitative research on atrial fibrillation (AF) patient's experiences and perceptions of taking the non-vitamin K antagonist oral anticoagulants (NOACs) for stroke prevention is limited. This study explores patients' experiences of NOACs and their recommendations for development of educational materials.

**Patients and Methods:** Semi-structured individual interviews with 8 warfarin-naive and 8 warfarin-experienced AF patients, using qualitative deductive thematic analysis.

**Results:** The four main overarching themes included: understanding the diagnosis; reaching a treatment decision; challenges of living with OAC; and patient perceptions of treatment. Patients discussed their shock of diagnosis, and seeking information and support at that time. Narratives suggest patients preferred to be led by the doctor when making treatment decisions, and would often compare NOACs to warfarin. Patients reported side-effects and challenges with both treatment options, and discussed their beliefs surrounding medications, including misconceptions. In addition to the original framework, two further themes were added: challenges of living with AF, and patient recommendations. Generally patients found AF symptoms distressing, which impacted their quality of life. Patient recommendations included the content and delivery of educational materials and development of tools to help with their understanding of AF and anticoagulation, as well as treatment adherence and anxiety surrounding symptoms and side effects.

**Conclusion:** Patient recommendations emphasised the need for interventions to relieve anxiety surrounding the diagnosis and possible treatment side effects. Tailored 'disease-specific' support is essential to ensure efficacious treatment. This qualitative study highlights the need for patient involvement in the development of educational materials and resources for patients commencing treatment with NOACs.

**Key words:** atrial fibrillation, non-vitamin K antagonist oral anticoagulants, patient education, dabigatran, warfarin, anticoagulation.

## Introduction

Atrial fibrillation is an independent risk factor for stroke,<sup>1</sup> and life-long anticoagulant treatment is necessary to reduce this risk.<sup>2</sup> The NICE<sup>3</sup> and the ESC guidelines<sup>4,5</sup> recommend oral anticoagulation for non-valvular AF patients with one or more stroke risk factors (CHA<sub>2</sub>DS<sub>2</sub>-VASc score  $\geq 1$  in men and  $\geq 2$  in women). Warfarin has been the mainstay oral anticoagulant for the past 50 years; however four non-vitamin K antagonist (VKA) oral anticoagulants (NOACs), dabigatran, rivaroxaban, apixaban, and edoxaban are now available for stroke prevention in AF. The NOACs do not require routine monitoring, and have fewer restrictions on concomitant medication, alcohol consumption and diet; therefore patients now have a broader choice of OAC treatments.

The shift towards patient-centred health care emphasises the need to ensure that patients are actively involved in the decision making process. This process may be more important for AF patients due to the risks associated with AF and the available treatment options.<sup>15</sup> Further, contemporary AF clinical guidelines<sup>3-5</sup> advocate incorporation of patient preferences for treatment and support patient engagement in treatment decisions.<sup>16</sup> Shared decision-making is particularly important with OAC treatment for AF given the chronicity of the treatment and the bleeding risks associated with OAC.<sup>17</sup> Thus patients need to accept and be adherent to lifestyle and dosing recommendations.<sup>3,4</sup> Previous studies have found that patients' beliefs surrounding their medication can predict INR control (including time in the therapeutic range (TTR)) and poor anticoagulation control is associated with greater risk of thromboembolic and haemorrhagic complications.<sup>3,18,19</sup> However, little is known about patients' beliefs surrounding the NOACs.

Several recent studies have examined adherence to dabigatran based on the proportion of days covered (PDC) by prescriptions. PDC ranged from 67-97%, with most studies reporting good levels of adherence.<sup>20-23</sup> However, these studies rely on PDC as a measure of adherence, in practice this does not give the whole picture regarding medication adherence. In one study that included qualitative interviews, 30% of patients acknowledged missing tablets, and 20% reported bleeding complications.<sup>20</sup> It is important to determine factors that influence patient adherence to NOACs. A recent study demonstrated that patients with a higher CHA<sub>2</sub>DS<sub>2</sub>-VASc score, prior bleeding and higher morbidity were more adherent.<sup>23</sup> Consequently a greater risk of stroke and bleeding complications may heighten patients' perceptions of the necessity of their medication. This evidence provides further credence to the role of patients' beliefs, perceptions and understanding of their condition and treatment influencing their subsequent adherence

behaviour. One recent qualitative study conducted a thematic analysis of online patient forums and discussion groups<sup>24</sup> and found that patients were concerned about the safety and efficacy of dabigatran and asked questions about indications and contraindications, proper storage of the drug, and diet and drug restrictions and perceived side effects. Whilst this study highlights some important areas where patients are lacking essential information, there is a dearth of qualitative evidence to support the development of patient educational materials for this treatment.

Further evidence is needed surrounding patients perceptions, experiences and understanding of NOACs. This will give some insight into the educational needs of this patient group, which may differ for patients that have or have not experienced taking warfarin. This group comparison is particularly pertinent as patients will often be faced with the decision as to which treatment option is most suitable for them, and their previous treatment experiences may influence this decision. This qualitative study will explore the patient's lived experiences, and perceptions of AF and anticoagulation, and the educational needs of AF patients taking dabigatran for stroke prevention in those with previous warfarin experience and those who are anticoagulant-naïve.

## **Method**

### *Participants*

Patients aged  $\geq 18$  years, with an electrocardiogram recording of AF, and a  $\text{CHA}_2\text{DS}_2\text{-VASc}$  score  $\geq 1$ , who were suitable for OAC therapy, and currently receiving NOAC treatment were eligible for inclusion. The first group comprised 8 patients who had never taken warfarin (warfarin-naïve) and who had been prescribed dabigatran within the last 4 weeks. The second group were 8 patients who had previously taken warfarin (warfarin-experienced) but were now taking dabigatran. Warfarin-experienced were defined as those patients had taken warfarin for  $\geq 3$  months. This time-frame was chosen because patients often experience INR instability during the initial phase of warfarin initiation.<sup>25</sup> All the patients in the warfarin-experienced group were already receiving dabigatran prior to participating in this study; patients did not switch treatments as part of this study and non-adherence to warfarin was not a reason for switching to dabigatran for any patient. Patients with severe cognitive impairment and dementia were excluded from the study.

Eight warfarin-naïve and eight warfarin-experienced AF patients were recruited in order to compare the experiences and perceptions of these two groups and elicit any differences in educational needs.<sup>26,27</sup> A purposive sampling method was employed and participants were recruited for 'expertise' on having AF and receiving NOAC treatment.<sup>26</sup> Patients were screened from an AF outpatient clinic in Birmingham to identify patients receiving dabigatran. 62 potentially eligible patients were identified and the first 27 patients were contacted, with 16 agreeing to participate in the study.

This sample size was deemed feasible and sufficient to achieve data saturation based on our previous research<sup>28,29</sup> and that of others.<sup>30</sup> However, we aimed to recruit more patients if data saturation was not met. All eligible patients identified by two researchers (DAL, DEC) screening an AF clinic list and hospital notes of AF patients receiving dabigatran. All patients gave their written informed consent to take part in the study. The researcher who conducted the interviews and analysed the data was not involved in the direct clinical care of the patients, and had no knowledge of the patient prior to the study. The research protocol was approved by the Black Country Local Ethics Research Committee.

### *Procedure*

Patients were recruited from an AF clinic in a hospital outpatient department. After screening clinic lists and hospital notes, 62 eligible patients were identified. The first 27 patients were contacted, by one of the researchers via telephone to discuss possible participation in the study. Of those patients contacted 11 declined and 16 took part in the study. They received usual care from their secondary care team, which included AF and drug-specific counselling. At the time of this study patients were also asked if they would like to be contacted by the HeartMind programme which provided AF targeted education and telephone support. If they were interested in participating in the qualitative study they were sent an information sheet via the post detailing the study aims and procedures. Interested participants were then telephoned again to arrange a convenient time for them to be interviewed at the hospital. Semi-structured interviews were conducted utilising previously identified themes from a meta-synthesis of previous qualitative studies carried out with AF patients taking warfarin as a framework.<sup>28</sup> Questions were based on a semi-structured interview schedule, but led by the patient thus allowing for further sub-themes to emerge from the narrative. We also asked specific questions about patient's views and

recommendations for providing information to patients in the future; this included what patients felt they needed when they were diagnosed with AF and starting a new treatment regimen. We also asked patients about their knowledge and understanding of AF and of their NOAC treatment.

The researcher explained to participants that the interview was not a test, but rather we were interested in their experiences and recommendations, to help to benefit future AF patients in the development of patient resources. Each interview lasted between 45-75 minutes and were digitally recorded and later transcribed verbatim. Individual interviews were employed as these facilitate rapport between researcher and patient and allow greater flexibility with regards the exploration of the patients' individual experiences.<sup>31</sup>

### *Data analysis*

Qualitative research methods enable health sciences researchers to delve into questions of meaning, examine institutional and social practices and processes, and identify barriers and facilitators of change. Qualitative methods are concerned with the patients' description and/or the interpretation of what is happening to them and what it means to them. It provides a rich, in-depth description of participant experiences. The analysis technique adopted for this study was deductive thematic analysis, identifying and describing the data in relation to pre-existing themes identified by our group.<sup>28</sup> The interview schedule was also developed in relation to our previous qualitative work.<sup>29</sup> This method was chosen to enable researchers to directly focus on transferring the findings into practical recommendations, and to allow for direct comparison with previous findings from studies with AF patients taking warfarin. Additional themes that arose during the interviews were also documented and reported. An essentialist/realist theoretical framework was adopted as this could reflect the meaning of participants' reality.<sup>32</sup>

Data analysis was carried out concurrently with data collection, to enable researchers to recruit more patients to the study until data saturation was reached. This also allowed for refinement of the interview schedule. For example, additional questions regarding patient recommendations for future resources were added following patient narratives in initial interviews. As part of the data familiarisation process, transcripts were read several times and coded using short verbal descriptions. Initial codes were generated and their associated quotes were copied and pasted into a spreadsheet for comparison. On

the basis of these codes we then inductively identified sub-themes. Those sub-themes which fitted with our existing themes from previous research were categorised and other emerging themes were grouped into new themes. Themes were then reviewed and data extracts were re-read to ensure they were coded appropriately.

Thus whilst the overarching themes from our previous qualitative work with AF patients provided a template,<sup>29</sup> any additional emerging themes were also documented. The analysis was carried out in accordance with the guidelines of Braun and Clarke.<sup>32</sup> Patterns within the data were coded by two researchers independently (DAL, DEC). Data was coded at the semantic level, not extending beyond the surface meaning of messages. The final analysis and reporting was carried out in relation to previous findings and relevant health psychology theories including the Health Belief Model,<sup>33,34</sup> beliefs about medication<sup>35,36</sup> and the self-regulatory model of illness perceptions.<sup>37</sup> Where there were nuances requiring further investigation authors referred back to the original text to determine the true meaning of the narrative.

## **Results**

### *Patient demography*

Of the 8 warfarin-naive participants, the mean (SD) age was 72.1 (6.2) years and the group included 6 male and 2 female participants. Of the 8 warfarin-experienced participants, the mean (SD) age was 71.2 (9.9) years, and 5 females and 3 males were included. Warfarin-naive patients had been taking dabigatran for a mean of 0.4 years versus 3.7 years in the experienced group [Table 1].

### **Qualitative themes**

There were six main overarching themes, four of which were originally derived from our previous research<sup>29</sup> and included (1) Understanding the diagnosis, (2) Reaching a treatment decision, (3) The challenges of living with OAC, and (4) Patient perceptions of treatment. Two additional themes also arose (5) Challenges of living with AF, which was found inductively and (6) Patient recommendations, a pragmatic theme, initially raised by patients during their interviews and later added to the interview schedule in order to transfer the needs and concerns of AF patients into practical recommendations for

future educational tools. Each theme had several sub-themes which are discussed in turn in relation to the patients as a whole and by group (warfarin-experienced and warfarin-naïve) [Table 2]. Table 2 also highlights which themes were discussed by which group. Patient recommendations for practice are presented to inform the development of educational materials [Table 3]. The quotes which support each theme and sub-theme are presented in Table 4.

### *Understanding the diagnosis*

The first theme, 'Understanding the diagnosis', was divided into three sub-themes: cause, support/information seeking, and distress. Both warfarin-naïve and warfarin-experienced patients discussed the *cause* of their condition, often relying on their own perceived cause, rather than a medically diagnosed cause.

Cause was often attributed to lifestyle, heredity, and age [Table 4, 1(a)].

There were no differences observed between the warfarin-experienced and warfarin-naïve groups in the perception of the cause of their AF.

Many patients mentioned *seeking information and support* surrounding their condition via health care professionals and the internet. Those patients who were warfarin-naïve were more likely to discuss efforts to seek additional information and support. This may be due to their relatively recent diagnosis when compared to warfarin-experienced patients (0.4 versus 3.7 years) and their lack of experience with the condition and treatment. The warfarin-naïve patients posited several questions and concerns that remained unanswered [Table 4, 1(b)].

Other patients found the internet particularly useful.

The narratives of both groups discuss the shock of diagnosis, of starting long-term medication and for some, of experiencing a stroke. One patient discussed their distress surrounding these issues [Table 4, 1(c)]

### *Reaching a treatment decision*

The second over-arching theme was 'Reaching a treatment decision', and this contained four sub-themes: *OAC necessity, warfarin vs. NOAC, risk assessment, and 'doctor knows best'*. Only those patients who were warfarin-naïve discussed the necessity of anticoagulation; they did not view the decision as a matter of choice but rather a means of survival [Table 1, 2(a)].

Many of the warfarin-naïve patients discussed the decision to start taking a NOAC and used warfarin as a comparator. INR testing was discussed as a reason not to pursue warfarin treatment. For one patient INR monitoring was enough to deter her from warfarin as a treatment option [Table 4, 2(b)].

However, two other warfarin-naïve patients did mention the lack of an 'antidote' for NOAC when compared to warfarin, as a consideration that made the decision more difficult [Table 4, 2(b)].

Warfarin-naïve patients seem to conduct their own risk assessment when comparing treatment options. One patient considered treatment as providing an extended life expectancy whereas another warfarin-naïve patient was prepared to take a NOAC as all options carried potential risks [Table 4, 2(c)].

When discussing the decision making process patients from both groups mentioned the need for guidance and many of the narratives highlighted implicit trust in the medical profession – '*doctor knows best*'. Many patients advocated trust in medical staff to guide the decision making process [Table 4, 2(d)].

### *The challenges of living with anticoagulation*

The third overarching theme was the '*Challenges of living with anticoagulation*' and this was divided into five sub-themes: *adherence, side effects (and anxiety surrounding side effects), maintenance of a therapeutic INR, benefits of a NOAC versus concerns, and the benefit of OAC versus concerns.*

Warfarin-naïve patients discussed difficulty adhering to the NOAC tablet dosage, particularly the evening tablet. One patient mentioned seeking memory aids to aid adherence [Table 4, 3(a)].

Warfarin-experienced patients were more likely to discuss their experiences of warfarin, particularly INR control and factors which affected anticoagulation control. One patient mentioned their constant awareness of lifestyle restrictions and another discussed problems maintaining INR [Table 4, 3(b)].

Patients in both groups discussed the benefits of taking NOACs, particularly the maintenance of independence, not being constrained by the INR monitoring required with warfarin, [Table 4, 3(c)].

For some warfarin-experienced patients switching treatments was also a relief from experienced side effects of warfarin.

Patient concerns in both groups surrounded the current lack of an antidote for dabigatran<sup>1</sup> and a lack of understanding surrounding the mechanism of action for the drug [Table 4, 3(d)].

Few patients mentioned any benefits of taking warfarin, but one warfarin-experienced patient did discuss the benefits of INR monitoring and an 'antidote' [Table 4, 3(e)].

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<sup>1</sup> At the time of this study the antidote for dabigatran was not available.

INR testing and the burden of regular visits to the hospital or GP surgery associated with warfarin were mentioned numerous times by both warfarin-experienced and *warfarin-naïve* groups as one of the main reasons to take a NOAC.

Both warfarin-naïve and warfarin-experienced patients discussed side effects including bruising and bleeding. However, some patients did not experience any side effects at all. For some patients their experience of side effects whilst taking both treatments (warfarin and/or NOAC) affected their confidence and quality of life and was also a cause of anxiety for some patients [Table 4, 3(b)]. This sub-theme was only found in the warfarin-experienced group. These anxious thoughts could lead patients to assume that any discomfort or 'new feeling' needed to be attributed to their condition or treatment [Table 4, 3(b)].

#### *Patient perceptions of treatment*

The fourth overarching theme was 'Patient perceptions of treatment' and this was split into three sub-themes: *beliefs about medication, poor understanding of OAC, and treatment as a cure or control*. Patients' narratives from both warfarin-experienced and warfarin-naïve groups surrounded their *beliefs about their medication* and their reluctance to take it. For one *warfarin-naïve* patient, taking medication was a reminder that he was getting older and more dependent. For another patient taking medication seems to represent a loss of independence [Table 4, 4(a)].

Some warfarin-naïve patient narratives highlighted a poor understanding of the effects of their treatment. For example one patient thought that NOAC treatment cured their irregular heart beat. Another patient presumed her blood was much thicker than normal prior to commencing treatment [Table 4, 4(b)].

Patients from both groups believed they had no control over their health or the outcomes, which caused disinterest in their treatment. However, for others they remained hopeful that their treatment would provide a cure or control for their condition [Table 4, 4(c)].

### *The challenges of living with atrial fibrillation*

The fifth overarching theme which emerged from these interviews was the '*Challenges of living with AF*' sub-divided into symptoms and the impact on quality of life.

Many patients discussed the symptoms they experience as a result of AF, these occurred in both warfarin-naive and warfarin-experienced patients, and included palpitations and breathlessness. For some patients this affected their quality of life [Table 4, 5 (a)]. However, the majority of patients grew accustomed to their side effects, or did not experience any side effects. Some patients misattributed symptoms to age or other factors.

Patient narratives often mention anxiety surrounding their condition and how patients cope and the impact of this on their quality of life. AF had a negative impact on quality of life for both groups of patients and for some the risk of stroke was a source of anxiety. Some patients reported changing their lifestyle to accommodate their AF [Table 4, 5(b)]. But many recommended a 'worry-free' approach and continued their daily lives as normal as possible with AF having little impact on their quality of life [Table 4, 5(b)].

### *Patient recommendations for education*

During their interviews patients gave several recommendations for patient-centred management of AF. These included (1) social support, (2) information delivery, (3) illness-specific information, (4) relaxation techniques, and (5) memory aids. There were no group-specific recommendations and both warfarin-experienced and warfarin-naïve patients expressed a need for educational tools and patient support. Patients were providing guidance for the future and highlighting areas where they felt information was currently lacking.

Patient narratives included examples of patients from both groups that are information seeking, and those that avoid information.

Patients also differed on whether they seek social support, but both groups' elicited narratives suggestive of a need for social support at diagnosis and when commencing treatment. Some recommended group support to aid social comparison rather than one-to-one support.

'Table 3 provides a summary of patient recommendations for practice. Both groups of patients discussed a need for illness-specific educational materials. Whilst many patients recall receiving information surrounding treatment, few received any materials regarding their AF. Patients had specific questions that could be answered via these materials. They also recommended the use of visual aids to explain the link between AF and stroke and case studies or patient stories from patients that have experienced and coped with an AF diagnosis and treatment. Memory aids and relaxation techniques were discussed in detail, as many patients reported forgetting to take their tablets (particularly in the evening) and anxiety when experiencing symptoms which they perceived were related to AF.

## **Discussion**

This study gives unique insight into patients' experience of AF. Patient experiences varied widely with some themes reporting opposing findings. For example, some patients sought information from numerous sources, whilst others deliberately avoided it. Additionally some patients reported shock and distress at their diagnosis, while others found it made little difference to their quality of life. AF patient's

experiences and perceptions can differ based on the time since diagnosis, whether or not they are symptomatic, their perceptions surrounding medication and experience of treatment and side effects. The patient experience is complex, and yet the data suggests that most patients need more support. Patient narratives revealed misunderstandings of both the condition and treatment, supporting previous qualitative evidence.<sup>53</sup> Without the knowledge to facilitate the link between their illness (AF) and the necessity for treatment (stroke risk reduction), many patients may not view their condition as risky and indeed may underestimate the necessity of their medication, ultimately making misinformed decisions (i.e., choosing not to start treatment, not to be adherent or to permanently discontinue therapy). This is a concept supported by both the Health Belief Model<sup>33,34</sup> and Leventhal's self-regulatory model.<sup>37</sup>

When diagnosed with AF, narratives suggest most patients seek information surrounding their condition. It is important at this point that the information they gather is accurate, and that healthcare professionals provide adequate sign-posting to appropriate forums for support. A recent European Heart Rhythm Association (EHRA) position document summarises the latest information on patient preferences for the management of AF and provides details of appropriate patient resources.<sup>16</sup> Previous research has also highlighted the need for educational materials for AF,<sup>12,16,54</sup> and found that providing education and strategies to adapt necessary behaviours/lifestyle changes can improve INR control when commencing warfarin.<sup>18</sup> Patients' beliefs about their medication appear to play a vital role in their decision to adhere to medication and lifestyle recommendations.<sup>18</sup> Thus understanding patients concerns about their treatment and addressing them at this initial stage should be an important part of their clinical care. Indeed the themes raised by patients mirror the basic topics covered on the EHRA patient website ([www.afib.org](http://www.afib.org)). However, the patients in this study discussed practical and tangible tools which may not be accessible online, such as memory aids, relaxation techniques and social support. These are the support mechanisms that patients require face-to-face from their clinician or support group, in addition to educational resources.

AF can be a highly symptomatic condition in some, with patients reporting palpitations, dizziness, breathlessness, exercise intolerance and fatigue.<sup>4</sup> Thus, it is unsurprising that patients report a reduction in quality of life.<sup>54-58</sup> Learning to cope with these symptoms or starting treatment to alleviate symptoms could benefit a patient's quality of life and reduce psychological morbidity.<sup>59-61</sup> The patient

recommendations from this study suggest that relaxation techniques might be useful to reduce 'stress'. Patients discussed using breathing techniques and other activities when they experienced symptoms. More research needs to be done to investigate the anxiety levels of this patient group and to test interventions that could help to alleviate symptom-related distress. These interventions along with the provision of AF-specific education are particularly important for newly diagnosed patients, and screening for symptom burden can now be carried out as part of routine care using standardised measures.

Once diagnosed patients are faced with the decision as to whether they initiate treatment for stroke prevention. When reaching a treatment decision, the findings suggest patients rely on the knowledge and expertise of the doctor and trust their recommendations, highlighting the need for clear guidance on the treatment options on OAC therapy from the physician. It is also clear from the findings when patients change treatment (in this case from warfarin to dabigatran) it does not perhaps require the same decision making processes as when starting anticoagulation for the first time (see table 2). Indeed the narrative suggests that patients switching treatments only highlighted the theme 'doctor knows best' and did not discuss the risks and benefits of the different drugs at all. Thus education should be targeted towards newly diagnosed patients when making an initial decision about which treatment to adopt.

AF patient's beliefs about their medication can impact upon their decisions surrounding treatment and subsequent adherence.<sup>18,35,36</sup> Previous research with AF patients initiating warfarin found that when patients perceived their treatment as more harmful there was a decline in TTR, suggesting poorer adherence levels. When patients perceived treatment as a necessity, TTR was increased.<sup>18</sup> Perceived barriers could prevent behaviour change, a concept first introduced by the Health Belief Model, which has been applied to a wide range of health related behaviours.<sup>33,34</sup> These barriers may include the inconvenience, danger (e.g. side effects) or discomfort (e.g. associated anxiety) of the treatment. Narratives from this study do suggest anxiety surrounding treatment and diagnosis. As beliefs about medication can have an impact on whether patients choose to comply with regimes and recommendations, some of these concerns could be alleviated by the provision of adequate education and ensuring that patients understand the information they have been given.<sup>54</sup> Furthermore, individuals have to perceive the

benefits of treatment to outweigh the barriers,<sup>33,34</sup> thus an understanding of the value of their treatment choices, and its necessity for stroke prevention is essential.

Once patients have decided to commence treatment they are presented with several options. Until relatively recently the only OAC option for AF patients was warfarin, but now several NOACs are available. As with previous research, patients report the decision to initiate OAC therapy is often made by the doctors; with little patient involvement in the decision-making process,<sup>38</sup> although some patients preferred this approach. This lack of involvement often coincides with a high level of trust in medical expertise, as illustrated by the commonly-used phrase “doctor knows best”. Thus doctors need to be well equipped when discussing treatment options, using decision aids and educational tools to help explain the condition and differences between OAC treatment options. In this study the decision of which treatment to take was discussed by the warfarin-naïve patients. They compared the two OAC treatment options (warfarin vs. NOAC) when making a decision. While NOACs provided a better perceived quality of life with fewer restrictions on lifestyle, patients still discussed problems remembering to take tablets. Warfarin-experienced patients were more likely to discuss difficulties they had previously maintaining a therapeutic INR. Both OAC treatments provided a source of anxiety and worries over potential side effects. It is important to consider that those patients that were warfarin-naïve were also likely to be recently diagnosed, thereby being more likely to have recent experience in making this treatment decision. Whereas patients that were warfarin-experienced, may also have negative experiences associated with previous treatment (hence switching treatment) and thus are more likely to discuss these difficulties. Patients understanding and perceptions of the treatment options were sometimes inaccurate. The narratives gave numerous recommendations surrounding the information and resources required which could provide a template for the development of patient-centred tools for future use to enable informed decision making for patients starting OAC treatment.

Several studies have designed patient decision aids to ascertain a patients' ability to make decisions about their antithrombotic therapy.<sup>39-42</sup> Patients' decisions are highly variable and may often depend on prior treatment experiences and health outcomes.<sup>42</sup> Furthermore, using the decision aid does not necessarily

improve patient satisfaction when compared to a control group even though trial patients believed they were more informed.<sup>42</sup> Thus the development of decision aids for clinicians maybe more appropriate, incorporating information from the clinical trials on stroke risk reduction and safety (bleeding risks) with each of the NOACs and warfarin<sup>13, 43-45</sup> and overall net clinical benefit (stroke vs. intracranial haemorrhage).<sup>3, 46, 47</sup>. One tool, developed for clinicians, identifies the agent with the lowest net risk based on patient's baseline risk of stroke and major bleeding, as well as individual patient factors such as treatment threshold, bleeding ratio and cost threshold.<sup>48</sup> As all of the patients interviewed in this study would rather rely on the expertise of the doctor and their trust in the health care professionals than make the decision as to which treatment is appropriate themselves, physician should be cognisant that their patient will likely follow their advise. It is therefore important that clinicians are provided with appropriate tools to help with this decision making process, for example, relevant guidelines and simple mobile app tools to provide support [e.g. ESC 2016 mobile application software<sup>49</sup>]. However, it is also important to account for patients' current perceptions, experiences of side effects and symptoms, and their understanding of their treatment options, in order to provide adequate and tailored information for the patient as well as treatment recommendations.

Another factor that plays an important role in the decision making process is the patient's perception of risk.<sup>12,50</sup> Information on the risk of bleeding significantly attenuates the number of patients willing to take OAC, suggesting that patients 'trade-off' the risk of stroke with the risk of bleeding, to arrive at a decision about OAC therapy.<sup>51</sup> Qualitative evidence suggests that patients who decide not to take warfarin do not perceive themselves at high risk of stroke,<sup>52</sup> thus they may place greater emphasis on the 'unnecessary' risks of bleeding. The findings of this study also highlight the patient's assessment of risk, although this may not always be accurately informed and often patients rely on information from family, friends and the media, rather than healthcare professionals. Therefore providing accurate risk information, in an understandable format, prior to decision making could enable the patient to make an informed decision more easily or with greater confidence.

## **Limitations**

The use of deductive thematic analysis allowed this study to focus on the specific needs of patients in relation to previous research and the development of future resources. However, in using this type of

analysis there is a risk that important insights into patient's experiences were missed by trying to fit the data to existing themes. We attempted to overcome this by documenting additional themes when they arose in the patient narratives. However, an inductive approach may have provided more detailed insight into the patients lived experience of AF diagnosis and treatment commencement. Further, patient education as a theme arose from initial patient narratives and we then added some questions about patient resource needs to the interview schedule for future interviews. In specifically asking patients about their recommendations resources, this may have biased outcomes. However, we feel this was justified in order to provide information which enables the development of patient-focussed materials, based on lived experiences and real patient narratives. Further, we did not carry-out member checking for respondent validation, which would have increased the internal validity of our findings, thus there is a risk that our interpretation of the narratives do not represent patients experiences and intended meaning.

As a qualitative single-centre study, based on one NOAC (namely dabigatran) the generalisability of the findings may also be limited. All but one patient in the study was aged 65 years or older and although this is the demographic of the AF population (mainly elderly), the views and opinions expressed may not reflect those of younger (<65 years) AF patients. Findings do however support those previously found by our group, and highlighted in previous qualitative studies with other cohorts.<sup>28,29</sup> At the time this study was conducted dabigatran was the only licensed NOAC available in the UK. Since then other NOACs have become available. We have no reason to believe that the findings from this study are not applicable to other NOAC treatments.

## **Conclusion**

Whilst NOACs do not require the same lifestyle restrictions as warfarin, they do rely on patient adherence to ensure safety and efficacy. The findings suggest that patient beliefs and misconceptions exist surrounding their treatment (OAC) and condition (AF) which could impact on their ability and willingness to adhere to treatment recommendations. Patients provided numerous recommendations based on their treatment experiences that could be utilised when developing educational materials such

as the inclusion of illness-specific information, memory aids, relaxation techniques and visual aids. Further research is needed to examine the impact of these proposed materials on patient adherence and clinical outcomes.

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## **Conflicts of interest**

**GYHL:** Steering Committees/trials: Includes steering committees for various Phase II and III studies, Health Economics & Outcomes Research, etc. Investigator in various clinical trials in cardiovascular disease, including those on antithrombotic therapies in atrial fibrillation, acute coronary syndrome, lipids, etc. Consultant for Bayer/Jensen J&J, Astellas, Merck, Sanofi, BMS/Pfizer, Biotronik, Medtronic, Portola, Boehringer Ingelheim, Microlife and Daiichi-Sankyo. Speaker for Bayer, BMS/Pfizer, Medtronic, Boehringer Ingelheim, Microlife, Roche and Daiichi-Sankyo.

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**DEC** has no conflicts of interest to declare.

These conflicts of interest do not alter our adherence to policies on sharing data and material.

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**Table 1: Participant demographics**

| <b>Participant number</b> | <b>Sex</b> | <b>Warfarin experience</b> | <b>Age</b> | <b>Number of years taking dabigatran</b> | <b>CHA<sub>2</sub>DS<sub>2</sub>-VASc Score</b> |
|---------------------------|------------|----------------------------|------------|--|---|
| <b>P1</b>                 | Male       | Naïve                      | 72         | 0.25                                     | 2   |
| <b>P2</b>                 | Male       | Naïve                      | 69         | 0.25                                     | 3   |
| <b>P3</b>                 | Female     | Naïve                      | 83         | 0.5                                      | 6   |
| <b>P4</b>                 | Female     | Naïve                      | 68         | 0.25                                     | 3   |
| <b>P5</b>                 | Male       | Naïve                      | 67         | 0.5                                      | 1   |
| <b>P6</b>                 | Male       | Naïve                      | 79         | 0.25                                     | 3   |
| <b>P7</b>                 | Male       | Naïve                      | 65         | 1  | 1   |
| <b>P8</b>                 | Male       | Naïve                      | 74         | 0.25                                     | 4   |
| <b>P9</b>                 | Male       | Experienced                | 71         | 5  | 1   |
| <b>P10</b>                | Female     | Experienced                | 75         | 5  | 6   |
| <b>P11</b>                | Female     | Experienced                | 79         | 5  | 4   |
| <b>P12</b>                | Female     | Experienced                | 58         | 0.5                                      | 2   |
| <b>P13</b>                | Female     | Experienced                | 79         | 0.25                                     | 4   |
| <b>P14</b>                | Male       | Experienced                | 80         | 6  | 6   |
| <b>P15</b>                | Female     | Experienced                | 55         | 2  | 3   |
| <b>P16</b>                | Male       | Experienced                | 78         | 6  | 5   |

**Table 2: Main themes and sub-themes, including which themes were discussed by warfarin-experienced and warfarin-naïve patients**

| Main theme                           | Sub-theme  | Warfarin-experienced | Warfarin-naïve |
|--------------------------------------|--|----------------------|----------------|
| 1. Understanding the diagnosis       | (a) Cause  | ✓                    | ✓              |
|                                      | (b) Support/information seeking                      | ✗                    | ✓              |
|                                      | (c) Distress   | ✓                    | ✓              |
| 2. Reaching a treatment decision     | (a) OAC necessity                                    | ✗                    | ✓              |
|                                      | (b) Warfarin vs. NOAC                                | ✗                    | ✓              |
|                                      | (c) Risk assessment                                  | ✗                    | ✓              |
|                                      | (d) Doctor knows best                                | ✓                    | ✓              |
| 3. The challenges of living with OAC | (a) Adherence  | ✗                    | ✓              |
|                                      | (b) Side effects (+anxiety surrounding side effects) | ✓                    | ✓              |
|                                      | (c) INR maintenance                                  | ✓                    | ✗              |
|                                      | (d) NOAC benefit vs. concerns                        | ✓                    | ✓              |
|                                      | (e) OAC benefit vs. concerns                         | ✓                    | ✓              |
| 4. Perception of treatment           | (a) Beliefs about medication                         | ✓                    | ✓              |
|                                      | (b) Poor understanding                               | ✗                    | ✓              |
|                                      | (c) Cure/control                                     | ✓                    | ✓              |
| 5. Challenges of living with AF      | (a) Symptoms   | ✓                    | ✓              |
|                                      | (b) Impact on quality of life                        | ✓                    | ✓              |
| 6. Patient recommendations           | (a) Social support                                   | ✓                    | ✓              |
|                                      | (b) Information delivery                             | ✓                    | ✓              |
|                                      | (c) Illness specific information                     | ✓                    | ✓              |
|                                      | (d) Relaxation techniques                            | ✓                    | ✓              |
|                                      | (e) Memory aids                                      | ✓                    | ✓              |

**Table 3: Patient recommendations for support and educational materials**

| <b>Recommendation</b>               | <b>Implementation</b>   |
|-------------------------------------|---|
| <b>Social support</b>               | <ul style="list-style-type: none"> <li>• Case studies of others that have had AF and started treatment</li> <li>• Commonly asked questions and their answers</li> <li>• Links to social support networks and support groups (online and face-to-face)</li> </ul>  |
| <b>Information delivery</b>         | <ul style="list-style-type: none"> <li>• Include visual aids to illustrate what happens to the heart during AF and stroke and the link between the two</li> <li>• Provide information at appropriate times, for example avoiding over burdening post-stroke.</li> <li>• Provide information in layman's terms with signposting to additional detailed information online or through charities.</li> </ul> |
| <b>Illness specific information</b> | <ul style="list-style-type: none"> <li>• Provide an explanation of the known causes and consequences of AF</li> <li>• Include information on the types of AF</li> <li>• Provide information on the investigations that take place with AF</li> <li>• Provide information on any lifestyle changes that patients should consider due to their condition</li> </ul>   |
| <b>Relaxation techniques</b>        | <ul style="list-style-type: none"> <li>• Include information on how to avoid anxiety associated with treatment and diagnosis</li> <li>• Include guidance on relaxation and breathing techniques</li> <li>• Include information on identifying triggers for palpitations and other side effects</li> </ul>   |
| <b>Memory aids</b>                  | <ul style="list-style-type: none"> <li>• Provide memory aids</li> <li>• Sign post to charities that provide reminder services</li> </ul>  |

- The potential to develop a memory aid app for mobile phones and tablets

**Table 4: Example patient quotations for each sub-theme**

| Main theme                       | Sub-theme                           | Quotes   |
|----------------------------------|-------------------------------------|--|
| 1. Understanding the diagnosis   | (a) Cause                           | <p><i>'...So, I'm thinking to myself it's my own lifestyle. I think lifestyle has a lot to do with it to be quite honest. I do. You can abuse your body too much' [P9, experienced, male].</i></p> <p><i>'I put it down to my mother had high blood pressure and I take after her that way' [P14, warfarin-experienced, male].</i></p> <p><i>'Age .....It's the only thing I can think of, age. Which is another question I asked him and I got the usual answer off medical people, could be, may not be' [P1, warfarin-naïve, male].</i></p> |
|                                  | (b) Support and information seeking | <p><i>'Just what it was, and all other effects and things that related to it, and quite frankly I found nothing' [P1, warfarin-naïve, male]</i></p> <p><i>'Off the internet, just reading and reading.... It's very good actually' [P4, warfarin-naïve, female].</i></p>   |
|                                  | (c) Distress                        | <p><i>'It was quite upsetting because everybody thinks they're going to live forever. First of all having the stroke was a really big wakeup call.... because I didn't smoke or drink anyway, healthy diet. Then to be told that I've got to take medication every day for the rest of my life ...that was horrible' [P15, warfarin-naïve, female].</i></p> <p><i>Yes, it was a little bit frightening and a bit of a shock because up until then I'd been reasonably healthy' [P11, warfarin-experienced, female].</i></p>                    |
| 2. Reaching a treatment decision | (a) OAC necessity                   | <p><i>'I: And what's your motivation to take them? P: because I have to... no other, at the moment I am told I have to' [P1, warfarin-naïve, female].</i></p>  |

|                                      |                       |  |
|--------------------------------------|-----------------------|--|
|                                      |                       | <p><i>male].</i></p> <p><i>'I only see it as something I have to do, because of something I might or I have got, I don't feel any different at all from the day before or the day after' [P1, warfarin-naïve, male].</i></p>   |
|                                      | (b) Warfarin vs. NOAC | <p><i>'With the one I'm on I don't have to have blood tests. With warfarin you have to keep coming back to get your blood levels correct.... Oh, I couldn't be doing with that' [P4, warfarin-naïve, female].</i></p> <p><i>'Yes, it sounded very convenient although of course I know there's no antidote like warfarin' [P7, warfarin-naïve, male].</i></p>  |
|                                      | (c) Risk assessment   | <p><i>'I suppose it gives me the potential for living longer from that point of view' [P5, warfarin-naïve, male].</i></p> <p><i>'Oh right, okay fair enough, it's a change from something that's got a risk to something that probably has got a different sort of risk' [P8, warfarin-naïve, male].</i></p>   |
|                                      | (d) Doctor knows best | <p><i>'You're trusting what you've been given, and go hopefully forward' [P3, warfarin-naïve, female].</i></p> <p><i>'Take the advice that the hospital gives you. I think that's one of the main things, listen to the doctor or nurse, whoever it may be, listen to them, because they don't tell you for nothing. They don't just tell you for the sake of opening their mouths and talking to you, they tell you for your own benefit and your own good' [P14, warfarin-experienced, male].</i></p> <p><i>'At the end of the day I'm not the doctor, I'm the patient. I like to be guided' [P7, warfarin-naïve, male].</i></p> |
| 3. The challenges of living with OAC | (a) Adherence         | <p><i>'The hardest one to remember is the evening one isn't it; I miss that</i></p>  |

|  |   |  |
|--|---|--|
|  |   | <p><i>one almost every night' [P1, warfarin-naïve, male].</i></p> <p><i>'I had contact from the Heart and Mind<sup>2</sup> group down in London. To start with, I was getting the text morning and evening because it was difficult sometimes to remember the evening tablet' [P5, warfarin-naïve, male].</i></p>  |
|  | <p>(b) Side effects<br/>(+anxiety surrounding side effects)</p> | <p><i>"I fell over. I came here, I bruised all my arm' [P10, warfarin-experienced, female].</i></p> <p><i>'She (daughter) thought I was having a stroke, she rang for an ambulance. I was rushed into here and I was in theatre for four hours and I lost 70% of my blood...I think I had been on antibiotics and one didn't agree with the other' [P11, warfarin-experienced, female].</i></p> <p><i>'I've had no side-effects whatsoever – none whatsoever as far as I know' [P8, warfarin-naïve, male].</i></p> <p><i>'It is just at the back of your brain isn't it; my brain won't let it go. My husband would love to go on holiday but I haven't got the confidence to go. I am just worried' [P11, warfarin-experienced, female].</i></p> <p><i>'I suddenly have thoughts of I'm going to start bleeding everywhere. I was really quite frightened' [P11, warfarin-experienced, female].</i></p> <p><i>'the problem is when you take something new is that any twinge that you get, any feeling, you think it's down to that' [P12, warfarin-experienced, female].</i></p> |

<sup>2</sup> The HeartMind scheme was a patient programme run by Boehringer Ingelheim for patients using dabigatran. It provided targeted education, telephone support and text reminders.

|  |                                      |   |
|--|--------------------------------------|---|
|  | <p>(c) INR maintenance</p>           | <p><i>'actually on warfarin and I know there's a lot of regular blood testing and stuff like that and it's a bit of a 'bug-bare' and booking appointments with the GP etc. on a pretty regular basis and I know the dabigatran sort of gets rid of that really' [P2, warfarin-naïve, male].</i></p> <p><i>'Not having warfarin is lovely, no bleeding or nothing' [P10, warfarin-experienced, female].</i></p> <p><i>'I was conscious that I was taking warfarin and certain things like if you take too much of one thing, like broccoli or avocado, pears and various other things, if you abuse yourself in certain - and alcohol as well, obviously, it can affect your INR reading' [P9, warfarin-experienced, male].</i></p> <p><i>'I mean, when I'd been taking it for some time and I'd got the level, I was going there regularly and I got the level to between two and three...I went there after six weeks and it was over six' [P9, warfarin-experienced, male].</i></p> |
|  | <p>(d) NOAC benefit vs. concerns</p> | <p><i>'I don't like the fact that there's no antidote although I read today on the internet that they are looking into making one now. I don't understand how it acts on the blood. With warfarin I understood' [P15, warfarin-experienced, female].</i></p> <p><i>The fact that it's not monitored. How do we know it is working? The fact that I haven't had another stroke? That's a bit worrying' [P15, warfarin-experienced, female].</i></p>  |
|  | <p>(e) OAC benefit vs. concerns</p>  | <p><i>'I liked the fact that I came for an INR test as well. It was inconvenient but at least you knew whether you were okay or not. I liked the fact that there was an antidote' [P15, warfarin-experienced, female].</i></p> <p><i>'I don't want that, it's going to interfere....I usually do something most days. I thought, I can't keep trailing backwards and forwards getting blood tested' [P3, warfarin-naïve, female].</i></p>   |

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| 4. Perception of treatment      | (a) Beliefs about medication | <p><i>'Oh it's just eer, I think it's the first lesson of you falling apart, it's just a reminder that you're getting older and not younger' [P1, warfarin-naïve, male].</i></p> <p><i>'I don't like taking pills...I don't know really...I've got to the age of 70 without taking a pill, I never have a headache unless I bang my head and it's something that's foreign to me, and I've got this thing about, I wonder if I can get to 90 without taking a pill' [P1, warfarin-naïve, male].</i></p> |
|                                 | (b) Poor understanding       | <p><i>'The benefits are that it stopped my atrial fibrillation, it's as simple as that' [P6, warfarin-naïve, male].</i></p> <p><i>'I know it's your blood, it's thicker, but you cut yourself and it flows quite freely, it's not coming out in lumps, which is almost the impression you get when you're told that your blood is thick, that it's coming out a bit like custard, but it doesn't, it just flows quite happily' [P3, warfarin-naïve, female].</i></p>                                    |
|                                 | (c) Cure/control             | <p><i>'I'm not really interested in heart regulation because I know that if I'm going to go, I'm going to go' [P10, warfarin-experienced, female].</i></p> <p><i>'That's one of the things, you think when you take any medication, you have miracle hopes, let's face it. It doesn't always follow, but that's your expectation' [P3, warfarin-naïve, female].</i></p>   |
| 5. Challenges of living with AF | (a) Symptoms                 | <p><i>'you could understand it if you were moving quickly, that you'd got palpitations, but if you were sat in the chair or in bed and it suddenly started, that was an uncomfortable feeling, a sort of feeling of, not quite sure what's going on' [P3, warfarin-naïve, female].</i></p> <p><i>'I walked round the corner here and the wind just took my breath. I</i></p>  |

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|                            |                               | <i>just say that is the wind. I suppose my AF has got something to do with that as well' [P11, warfarin-experienced, female].</i>  |
|                            | (b) Impact on quality of life | <p><i>'I do sometimes think about having a stroke and think of the problems that I bring on the rest of the family, but hopefully it won't happen' [P13, warfarin-experienced, female]</i></p> <p><i>'I have packed up the chairmanship. I stepped down from that with the immediate effect in September because I knew I'd got a problem' [P6, warfarin-naïve, male].</i></p> <p><i>'I would say I'm totally unaware of it, it's had no repercussions in any area I can think of' [P1, warfarin-naïve, male].</i></p> <p><i>I'm lucky that I don't tend to worry. Well, they class me as laid back. I think that helps me' [P14, warfarin-experienced, male].</i></p> <p><i>I'm lucky that I don't tend to worry. Well, they class me as laid back. I think that helps me' [P14, warfarin-experienced, male].</i></p> |
| 6. Patient recommendations | (a) Social support            | <p><i>'I looked up atrial fibrillation. What is it? What causes it? How many people have it?' [P4, warfarin-naïve, female].</i></p> <p><i>'Really and truthfully I have never gone in depth about it because I have always believed a little knowledge is a dangerous thing where medicine is concerned' [P11, warfarin-experienced, female].</i></p> <p><i>Also case notes – people who've got it and how they feel...You can relate to people' [P4, warfarin-naïve, female];</i></p> <p><i>'Like a question and answer thing and other people's experiences and that's quite useful' [P2, warfarin-naïve, male].</i></p>   |