

# **Patients' and health professionals' views and experiences of atrial fibrillation and oral-anticoagulant therapy: a meta-synthesis**

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## **Abstract**

**Background:** Atrial fibrillation (AF) patients are prescribed oral-anticoagulant (OAC) therapy, often warfarin, to reduce stroke risk. However, it is under-prescribed and sometimes refused by patients. We explored existing qualitative evidence about patients' and health professionals' experiences of OAC therapy.

**Method:** Systematic searches of eight bibliographic databases were conducted. Quality was appraised using CASP and data from ten studies were synthesised qualitatively.

**Findings:** Four third-order constructs emerged: (1) *Diagnosing AF and the communication of information*, (2) *Deciding on OAC therapy*, (3) *Challenges revolving around patient issues*, and (4) *Healthcare challenges*. Synthesis uncovered perspectives that could not be achieved through individual studies.

**Discussion:** Physicians' and patients' experiences present a dichotomy of opinion on decision making, which requires further exploration and changes in practice. Outcomes of workload pressure on both health professionals and patients should be investigated. The need for ongoing support and education to patients and physicians is critical to achieve best practice and treatment adherence.

**Practice Implications:** Such research could encourage health professionals to understand and attend better to the needs and concerns of the patient.

**Keywords:** Meta-synthesis, Qualitative, Patient, Doctor, Experiences, Atrial fibrillation, Oral-anticoagulation therapy

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# **Patients' and health professionals' views and experiences of atrial fibrillation and oral-anticoagulant therapy: a meta-synthesis**

## **1. Introduction**

Atrial Fibrillation (AF) is the most common arrhythmia in clinical practice and is associated with increased morbidity and mortality. [1, 2] AF is an independent risk factor for stroke conferring a risk five times that of matched controls. [3] Hence, stroke risk reduction with antithrombotic therapy is a crucial component of AF management. [2, 4] Guidelines recommend life-long oral-anticoagulation therapy (OAC) for patients with one or more risk factors for stroke. [2] However, such therapy remains underutilised. [5, 6]

There are a number of complex factors which make prescription, and adherence, of OAC challenging. Physicians may display uncertainty about balancing the risk of stroke and the risk of bleeding, which may be passed onto patients. [7] Two recent systematic reviews emphasised the impact of physicians' apprehension about feeling responsible for a major bleed which seemed to outweigh their concern about risk of stroke. [8, 9] This may be related to the Hippocratic Oath to 'first do no harm' [10]: responsibility is attributed to harm perceived to be caused by 'acts of commission', i.e. prescribing OAC, which are not felt with 'acts of omission', i.e., increasing the risk of stroke by not prescribing OAC.

Very little is known about patients' understanding of AF and OAC treatment. What we do know is that patients with AF report poorer quality of life compared to the general population [4, 11], and greater levels of anxiety. [12]

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This review of the literature indicated a need to consolidate existing evidence about patients' and physicians' experience of AF and OAC. The complexity inherent in this field make the need for patient-centred care, effective communication skills, and individually-tailored education, as recommended by NICE [1], particularly significant. To determine what is already known, implications for practice and to indicate where further research should be focused we conducted a meta-synthesis of qualitative evidence examining patients' and health professionals' experiences and beliefs about AF and OAC therapy.

## **2. Method**

Meta-synthesis of qualitative evidence is modelled on traditional systematic review methodology [13] and this meta-synthesis follows the techniques described in Taylor et al. [14] A systematic search strategy, screening and quality appraisal were employed. Search terms were developed from two main bibliographic database categories: 'atrial fibrillation' and 'anticoagulant therapy'; a qualitative methodology filter was used to ensure the retrieval of qualitative studies [15] (see Appendix A for the full search strategy). Web of Knowledge, Ingenta connect, ScienceDirect (EBSCO), Swetswise, Sage Journals online, PsycInfo and the Cochrane Library were searched to include publications up to 26th August 2011. The UK electronic theses online service (EThOS) and Google scholar were searched to identify UK dissertations and grey literature.

Studies retrieved were screened using the following inclusion criteria: studies that explored views or experiences of patients or carers and/or health professionals (e.g.

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physicians and/or nurses and/or pharmacists) about AF and/or OAC using qualitative methods (defined as using qualitative techniques for recruitment strategies, data collection, and data analysis). Once screened, duplicates were removed and reference checking and citation searches were conducted. Some authors were contacted directly if data or methodological information were missing.

The quality of studies was appraised using the Critical Appraisal Skills Programme (CASP) Tool for qualitative research [16], independently by the research team (CBX, RS, DAL), who then met to agree the quality rating. Papers deemed to be of low quality were not excluded but their findings were given less “weight” during the synthesis process [17].

Synthesis proceeded following the principles outlined by Malpass et al. [18]. Articles were read in-depth and their findings recorded in data extraction forms. Key themes and categories were identified (first-order constructs) and grouped through descriptive coding to form second order constructs (See Table 2). The synthesis then involved the interpretative activity of translating studies into each other, i.e. comparing and contrasting themes across papers to identify super-ordinate themes, or third-order constructs, which represent the collective meanings of findings from individual papers to enable a theoretical interpretation of the phenomenon. This was facilitated by the use of mind maps to think through interrelations between first- and second-order constructs within and between papers to ensure the development of third-order constructs remained true to the data throughout the synthesis (See Figure 1 and Table 2).

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### **3. Results**

The topic-based search terms yielded over 100,000 references but with the qualitative methodology filter this number was reduced to 12 unique studies (see Figure 2). Two studies were excluded: one explored experiences of patients with an implantable atrial defibrillator; another was a method-based paper about using qualitative research to discontinue one arm of a trial. Ten studies met the inclusion criteria and were included in this meta-synthesis (see Table 3 for summary of characteristics). The four third-order constructs identified are presented in series (see Table 2).

#### **3.1 Diagnosing AF and the communication of information**

Only McCabe et al. [19] explored patients' pre-diagnosis experiences. They found that some were diagnosed accurately and quickly, whilst for others the process was slow because arrhythmia is difficult to document on an ECG and AF symptoms are not always clear which led to some patients being misdiagnosed with stress. Murray et al [20] was also found a lack of agreement on the severity of AF and physicians expressed a lack in confidence in detecting paroxysmal AF (i.e. self-terminating episodes of AF typically lasting <48 hours but no longer than 7 days) due to its intermittent nature. Nevertheless, once AF was diagnosed, patients reported a sense of relief despite this sometimes being shocking news. [19]

“The doctor came in and said: “The good news is you’re not crazy. The bad news is there is something wrong.” I’m like - I told you - you should have believed me in the first place. It was almost a relief - not that something was

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wrong with my heart, but that at least I know something's wrong. It may be fixed versus going on feeling yucky and not getting an answer.” (Patient) [19]

Participants from three studies [19, 21, 22] found that additional information on possible treatments to control AF symptoms and OAC was lacking. According to their participants' accounts, educational efforts aimed at increasing knowledge about AF and warfarin were minimal and insufficient.

“Nobody really explained to me in full what Coumadin is all about, but I did some reading about it. I know it's a blood thinner, an anti-coagulant... helps with the atrial fibrillation that I have, because apparently blood stays longer than it should in the atrium, and if it thickens it can go to your brain and you can have a stroke.” (Patient 8) [21]

This viewpoint is corroborated by health-care professionals in Bajorek et al [22] study who suggest that the educational information provided is often inadequate to the point that existing educational resources are not readily employed. Furthermore Lipman et al. [23] explored with General Practitioners (GPs) what educational information on OAC was discussed during consultations. More than half reported that they gave a limited amount of information about risks of warfarin to the patient.

“... I don't use risk tools, facts and figures it's a... more of a generality of erm... 'It's just going to reduce your risk of stroke and it should prolong

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your life' and erm... ..you know maybe I shouldn't but I don't have... I don't use NNTs [Number Needed to Treat]" (GP 10) [23]

Indeed, GPs were found to have different communication styles with varying rates of success. Some GPs preferred discussing statistics about risks associated with warfarin to help the patient reach a decision about warfarin uptake, while others preferred to avoid probabilities and statistics and instead offered a more doctor-led style. [23]

Patients commented that information during the consultation is often rushed. The following patient suggested that written information should be given, which could be further explained by the GP.

“The cardiologist . . . says you should cut out certain food, vegetables, or reduce the quantities . . . I found it very difficult to sit on the other side of his desk and try and make notes of what he was saying. Now to him it is a regular thing, it is a routine thing . . . for me it is the first time I hear this. For 50 years I have been eating this or that . . . I don't think it should be left verbally . . . (You) should be given a briefing sheet or something to take away . . . (then) see your GP and he follows this up with verbal advice.”  
(Patient) [22]

A further complication is that diagnosis or treatment advice may be given in secondary care. This is not always the best context for patients to take in the information provided.  
[24]

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“Education in the hospital ward...you are asking a lot when somebody is in a four bedded room...(pharmacist) trying to explain something to you...you can't hear, you can't sleep very well...probably not the best place for you to have all this stuff explained to you...only so much we can do, it's just too hectic.” (Nurse) [24]

### **3.2 Deciding on OAC therapy**

Following information provision at diagnosis is the decision-making process regarding OAC therapy. Again the literature reveals a mix of strategies. Three studies explored OAC therapy decision-making with patients [21, 22, 24], and in each patient's reported that the decision was taken by the doctor and that they were happy with this approach.

“I can recall that I had no objection. I said, "*You are the experts, you are the doctors. If I get any help, I mostly will appreciate it.*" .... I don't think I would trust myself that much (to make the right decision).” (Patient 15) [21]

However, other health professionals (nurses, hospital pharmacists) caution against this didactic consultation style, where a patient accepts a drug based on the trust they have in the expert [22, 24]. The argument was postulated that patients should be responsible for their health and voice their concerns, rather than abdicating responsibility for health care decisions to their doctor.

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“A lot of the older patients – ‘my doctor says it is good for me so I’ll take it...they are an expert’...are pretty bad because they don’t ask questions.”

(Nurse) [24]

Some patients wanted sufficient information to make an informed decision but also required time to reflect on it before discussing it further with their GP.

“I would personally prefer that I read the book first and then come back and say “I am not sure about this or that; could you explain this to me?” (Patient)

[22]

Dantas et al. [21] found that some patients had commenced OAC while hospitalised because of an emergency or another illness and therefore preventing an active informed decision. Under these circumstances patients often ended up being presented with warfarin as their only therapeutic option which is perceived as a problem by some [21, 22, 24].

When I went into the (clinic) to see my doctor, they admitted me to the cardiac emergency, and they kept me there all day... I was in for just about a week... and when I was discharged the doctors explained that they were putting me on to certain medications, and Coumadin was one of them.

(Patient 10) [21]

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“They just don’t voice a concern about taking it because they don’t see they have any other option...just part of the treatment that’s been prescribed...they have to put up with it.” (Nurse). [24]

In contrast physicians perceived this decision-making process as more of a negotiation. [23, 25] All GPs and senior physicians in these studies argued that patients’ ideas, concerns and expectations about OAC therapy should be central to consultations but the conclusion was that there was “a range of views as to the extent to which physicians would allow patients to be the ‘final’ decision-maker”. [25]

“I like to advise... identify what the patient thinks they need, what I think they should have, and then if it’s acceptable we come to an agreement and we try to take it forward, it’s negotiation, try more and more nowadays to do that in a consultation...” (GP1) [23]

“I would almost put the decision or the ball in his court and I would go down the lines of describing to him his absolute and relative risk reductions with aspirin and warfarin... and I’d see what he’d prefer to do” (Physician) [25]

However GPs feel responsible for the outcome (stroke or bleeding event) when a patient doesn’t take the “right” treatment decision. [23] This is more often the case with the ‘family-doctor’ relationship built over time, than hospital physicians. [23] These feelings often prevent GPs from prescribing warfarin for fear of causing bleeds.

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“Well it’s my fault for putting it in a way that . . . that perhaps didn’t put the benefits and harms quite in context. I’ve made a mistake in how I’ve described the risk for that individual patient because they made a decision which I think is probably the wrong decision . . .” (GP4) [23]

### **3.3 Challenges revolving around patient issues**

Researchers found that patients’ beliefs were influenced by their ‘experiential’ knowledge [26], that is knowledge gained through their experience. This knowledge often had a negative influence on warfarin acceptance. [21, 23, 27, 28] A common patient belief mentioned in these six studies was the awareness of warfarin being used as rat poison.

“‘Hang on doctor’ he said ‘That’s the stuff they use to poison rats with isn’t it’, I said ‘That’s . . . well it is and how do you . . . ’ and he said ‘Oh I was a rat catcher for the council, I don’t want that because I’ve seen too many things happen to rats with that’.” (GP1) [23]

Similarly, older participants in Fuller et al’s [28] study saw friends or family members have haemorrhagic strokes, and associated the increased risk of bleeding from OAC therapy with a possible haemorrhagic stroke. This could easily be misconstrued as the same medication that is lowering the risk of an embolic stroke is increasing the risk of a haemorrhagic stroke.

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“Bleeding into the brain – isn’t that fatal? Happened to someone I know”

(Patient 72, aged 78) [28]

Howitt & Armstrong [27] argued that patients who refused to take warfarin did not perceive themselves as vulnerable. Such patients believed that a stroke can only happen to people with an unhealthy lifestyle. This constitutes an avoidant coping mechanism, or denial, lived out in their agreement to take only aspirin.

“People who have strokes are overweight, drink and smoke. I don't think it will happen.” (Patient 16, final treatment aspirin) [27]

There are other issues related to lifestyle which resulted in refusal of, or a negative perception of, warfarin: the need for regular blood tests to monitor anticoagulation control, the amount of time it takes to do the tests, abstinence of alcohol, and an ever increasing amount of tablets. [19, 21, 23, 24, 28, 29]

“I’ve had one patient who has refused to go on warfarin . . . because he doesn’t want to take it, he doesn’t want to have that commitment to taking medication, to being monitored you know to possibly having the side effects that he might have, even though he is aware of the potential benefits, now if that’s . . . if that’s his decision that’s fine by me, it’s not my life, I’m not taking warfarin for the rest of my life you know.” (GP11) [23]

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Monitoring was reported as particularly disruptive when planning holidays or working. These patients were more likely to feel inconvenienced than those who were monitored less frequently. [29] Patients' resistance to follow-ups was also reported as a challenge. [20]

“I have to miss work to get my blood work done or go visit the doctor to get a prescription and depending on their hours, sometimes I have to leave.”  
(Patient US Group 6) [29]

However, some patients viewed the regular bloods positively as the monitoring confirmed their warfarin control. [21, 29]

“I like getting it checked. It makes me feel more comfortable, as far as know I'm okay.” (Patient US Group 11) [29]

### **3.4 Healthcare challenges**

Communication between primary and secondary care was a key challenge identified in the synthesis. [20, 22, 23] The lack of communication between hospital physicians and GPs meant neither took responsibility for patient education, which in turn has significant consequences for patient adherence. [22, 23]

“Decision making for who goes on warfarin is taken often by one person, monitoring of warfarin is taken by another person and in our practice people are monitored in 5 different systems, alright and er . . . ongoing

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responsibility for patient education is nonexistent . . . the potential risks of warfarin to me are so large in terms of errors basically.” (GP2) [23]

“It may create conflict with the patient too . . . especially if the other health professional said something (different)” (GP) [22]

The common problem of limited personnel and time pressures on consultation time was identified by health professionals, nurses and GPs as a barrier to investment in patient education. [22, 24]

“The doctors all roll up at 9 o’clock in the morning to do their rounds - ‘yep they can go home...there are five other people down in A&E waiting to come up, let’s ship them down to transit lounge.’ - they get home and open up this little plastic bag with all their drugs...pharmacist hasn’t had a chance to talk to them...we haven’t seen what they’re on...pressure to get them out. .” (Nurse) [24]

The nurse above and GP below suggested that since time is limited, responsibility to educate patients could be shifted to pharmacists, either at the hospital or in the community which may improve compliance. In addition, Bajorek et al [22] argued that such a strategy could aid patient surveillance and education.

If they are in there looking at the patient in-house . . . then that is probably quite useful . . . I usually don’t have the time . . . If the pharmacist is actually

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sitting down with them and looking at how they are managing their tablets at home . . . [monitoring] compliance [and] suggesting that the dosette is the way to go with this patient . . . It's a very practical way actually. (GP) [22]

#### **4. Discussion and Conclusion**

This meta-synthesis has enabled us to consolidate the knowledge about patients' and physicians' understanding of AF, risk perception management in relation to OAC therapy and the settings in which AF is diagnosed and treatment discussed. The National Institute for Health and Clinical Excellence guidelines [1] prioritise patient-led care which requires better rapport between physicians and patients.

Shared decision-making is imperative for patient-led care. Wirtz et al [30] discussed four models of patient-doctor decision-making (see Figure 3). Patients' experiences during the decision-making process synthesised here suggest a mixture of the paternalistic and interpretative models. While the physicians' experiences clearly indicate that a shared decision making model is being used. This contradiction warrants further study but could be related to the patient's trust in the expertise of the physician and may explain why patients submit to physicians' decisions. Evidence suggests that the concept of trust between patients and physicians is vital for a successful relationship [31, 32], which in turn is crucial for treatment adherence. Trust, in this case, is manifest in a positive acceptance of the sick role and belief that physicians will care for their

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interests [33]. In critical consultations, where potential risk and negative outcomes are discussed, what is interpreted as trust in the physician could also be due to the need to escape responsibility from a difficult decision.

Participants, both patients and health professionals commented that lack of time was an issue within the health-care system both with regard to patient education and physician workload. Deveugele et al [34] found that the mean length of consultations in the UK was almost 10 minutes. Similar to the findings of this synthesis, the literature suggests that this is not enough time to establish rapport with the patient, transmit information, and address the patient's needs [35, 36], which could have an effect on patient adherence to treatment. Developments in health psychology have resulted in several theoretical models for understanding variations in adherence to treatment. [37]

In explaining how beliefs might influence patients' decisions on adherence with prescribed medications, Horne [38] proposed that although beliefs about medicines in general influence the patients' initial orientation toward medicines, adherence behaviour is likely to be more strongly related to personal views about the specific prescribed medication. In particular, adherence decisions are influenced by a cost-benefit assessment in which personal beliefs about the *necessity* of the medication for maintaining or improving health are balanced against *concerns* about the potential adverse effects of taking it. [38] This means that within studies which have examined OAC therapy, patients' *concerns*, such as the knowledge of OAC side effects and the need for lifestyle change, outweigh the *necessity* of the medication in the reduction of thrombo-embolism. This may be due to the fact that OAC therapy is not a 100% fail-

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safe treatment and one can still encounter a stroke even though the risk is much lower. Therefore patients should be regarded as active decision makers who will be more motivated to use their medication if imparting of information targets the *necessity* of OAC outweighing their *concerns* about taking it. However further research on the lived experiences of physicians and patients is required to corroborate this. Such research could have an impact on practice, by encouraging health professionals to understand and attend better to the needs and concerns of the patient.

The benefit of incorporating qualitative evidence like that presented in this meta-synthesis within the larger hierarchy of evidence is that it can add depth; it can bring the focus back to the individual to ensure that population-based findings retain their applicability to the individual case. [39] The model of mixed evidence enables a holistic approach to evidence-based health care that contextualizes the biomedical data by also making sense of the social determinants of health which are critical when designing interventions for individuals leading complex lives. [40]

This meta-synthesis clearly identifies the key challenges facing AF patients and healthcare professionals who manage their treatment, namely the importance of an early and accurate diagnosis, necessity of sufficient education pertaining to AF and available treatment, particularly OAC, and identification of patient barriers to treatment to improve adherence. This qualitative meta-synthesis highlights that central to all these issues is the effective communication of information in a variety of formats by different healthcare professionals, and the need for an individualised approach based on

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discussions with patients regarding their preferences for decision-making and treatment options rather than a ‘one-size fits all’ approach.

**I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.**

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