

Patients' and physicians' experiences of atrial fibrillation consultations and anticoagulation decision-making: a multi-perspective IPA design

ABSTRACT

Objective: To explore patients' and physicians' experiences of atrial fibrillation consultations and oral anticoagulation decision-making.

Design: Multi-perspective interpretative phenomenological analyses.

Methods: Participants included small homogeneous subgroups: AF patients who accepted (n=4), refused (n=4), or discontinued (n=3) warfarin, and four physician subgroups (n=4 each group): consultant cardiologists, consultant general physicians, general practitioners and cardiology registrars. Semi-structured interviews were conducted. Transcripts were analysed using multi-perspective IPA analyses to attend to individuals within subgroups and making comparisons within and between groups.

Results: Three themes represented patients' experiences: *Positioning within the physician-patient dyad*, *Health-life balance*, and *Drug myths and fear of stroke*. Physicians' accounts generated three themes: *Mechanised metaphors and probabilities*, *Navigating toward the 'right' decision*, and *Negotiating systemic factors*.

Conclusions: This multi-perspective IPA design facilitated an understanding of the diagnostic consultation and treatment decision-making which foregrounded patients' and physicians' experiences. We drew on Habermas' theory of communicative action to recommend broadening the content within consultations and shifting the focus to patients' life contexts. Interventions including specialist multidisciplinary teams, flexible management in primary care, and multifaceted interventions for information provision may enable the creation of an environment that supports genuine patient involvement and participatory decision-making.

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Keywords: atrial fibrillation; oral anticoagulation; medication adherence; decision making; qualitative research; interpretative phenomenological analysis.

INTRODUCTION

Atrial fibrillation (AF) is the most common cardiac arrhythmia (irregular heart beat or ‘heart flutter’); some patients are symptomatic while others are not.¹ Lifetime risk of developing AF for adults over 40 is 1 in 4 and risk factors for incident AF are increasing age, male sex, hypertension, diabetes mellitus, and metabolic syndrome (Lane, Boos, & Lip, 2015b). Stagnation of blood in the atria can increase the risk of embolism and stroke; through reduced cardiac output it can lead to heart failure (Camm et al., 2012). Treatment for AF must safeguard against both. Stroke risk reduction involves ‘thinning the blood’, requiring a careful balance between the risks of stroke and bleeding. According to evidence-based NICE (2014) guidance, oral anticoagulation (OAC) is the most suitable treatment for stroke prevention in AF; warfarin is an effective and widely used OAC drug². However, OAC remains underutilised (Cowan et al., 2013; Kakkar et al., 2013). A recent survey of 1857 UK general practices revealed that 34% of AF patients at high-risk of stroke who were suitable for OAC were not receiving it (Cowan et al., 2013); similar OAC underuse was evident globally (Kakkar et al., 2013). Reasons for underutilisation of OAC are multifaceted but can be broadly divided into three categories: patient-, physician-, and healthcare system-related barriers (Gattellari, Worthington, Zwar, & Middleton, 2008a; Pugh, Pugh & Mead, 2011).

This study focused on warfarin and explored in-depth physicians’ and patients’ experiences of the diagnostic consultation, physicians’ information-provision regarding AF and OAC, and patients’ treatment decision-making processes. We know that patients’ illness perceptions impact on their treatment decisions, adherence, and their emotional, behavioural and cognitive responses to the illness (Leventhal, Brissette & Leventhal, 2003). Patients’ understanding of

¹ See the disease description from Patient Information UK: <http://patient.info/doctor/atrial-fibrillation-pro> (accessed 23/07/15).

² A new drug is now recommended by NICE, dabigatran etexilate, but the evidence base for this drug is not as established as that for warfarin. See: <https://www.nice.org.uk/guidance/ta249> (accessed 24/07/15).
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AF and warfarin is therefore paramount to their effective management of heart health and reduced stroke risk. Previous research has shown poor levels of understanding of warfarin (Lane, Barker, & Lip, 2015a; Borg Xuereb, Shaw, & Lane, 2012) which suggests the need for better information provision.

Warfarin requires regular monitoring (blood tests) to ensure the International Normalised Ratio (INR), which measures how long it takes the blood to clot; it must be kept within the therapeutic range (INR 2.0-3.0). Maintaining the therapeutic range requires an individual tailored approach to medication to determine the appropriate dose. Initially this may require blood tests every week until the INR has stabilised; blood tests are then often conducted monthly. It is not surprising that physicians have raised concerns about patients' ability to understand and adhere to the warfarin regimen and that patients report limited input in decision-making (Dantas, Thompson, Manson, Tracy, & Upshur, 2004). The inconvenience of blood tests and lifestyle changes (restrictions in relation to diet and alcohol), have significantly influenced patients' decisions to accept or decline warfarin and their long-term adherence (Dantas et al., 2004; Lipman, Murtagh & Thomson, 2004). There is clearly a need to identify ways of conveying complex information about long-term warfarin use in language that is easily understood by diverse patients groups which facilitates active patient involvement in treatment decisions.

Involving patients in decision-making requires skilled communication and a good relationship between physicians and patients. Contemporary medicine advocates a participatory decision-making process – concordance: following discussions about available treatment options, a decision is negotiated between healthcare professional and patient taking into account the beliefs and desires of the patient (Horne, Weinman, Barber, Elliott, & Morgan, 2005; Emanuel & Emanuel, 1992). This is a move away from the didactic, paternalistic model of the physician-patient relationship, which focused on the biomedical, toward a collaborative relationship

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involving shared decision-making where patients are construed as sentient, autonomous beings (Wirtz, Crib, & Barber, 2006). Participatory decision-making has become a target in UK government policy but translating the concept to the actual lived experience in everyday practice remains challenging. This study aimed to understand participatory decision-making within the context of consultations about AF and warfarin. To this end, an interpretative phenomenological approach was taken to focus upon the lived experience of both patients and physicians.

METHOD

Study design

Interpretative phenomenology was adopted as the methodological framework because it is concerned with how people make sense of their experiences. Interpretative phenomenological analysis (IPA) is an idiographic method usually involving single homogeneous samples with individuals who have experience of the phenomenon (Smith, Flowers, & Larkin, 2009; Smith, 2011). This study employs a “multi-perspective design” (Smith et al., 2009: 52, 160) by bringing together a network of subgroups. The phenomenon of interest is the consultation, and within that, participatory decision-making. In phenomenology, perception is fundamental to our experience of reality; our understanding of phenomena in the world is therefore partial and perspective, in that we can only perceive it through our own senses (Moran, 2000). If we examine the space *in between* individuals, their interactions with each other, and their co-constitutive meaning-making processes – or intersubjectivity – we are likely to gain a fuller understanding of the phenomenon (Loaring, Larkin, Shaw, & Flowers, 2015). Gaining experiential descriptions and interpretations of the consultation and decision-making from multiple perspectives will boost our understanding and help develop recommendations considering both patients and physicians.

Recruitment and sampling

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Purposive sampling was used to identify participants. Guidance from Smith et al. (2009) set the targets for each subgroup as 3-4. Ethical approval was granted by South Birmingham Research Ethics Committee to recruit patients from an AF hospital clinics and physicians from local primary and secondary care settings within the West Midlands, UK.

Patients

Patients were eligible for inclusion if they were aged ≥ 18 years and had been diagnosed with AF. Patients with severe cognitive impairment were excluded. Patients were recruited who had: accepted or declined warfarin, and those who had chosen to discontinue warfarin. Eligible patients were identified from screening hospital notes by four cardiology registrars.

Physicians

Physicians were eligible for inclusion if they had experience of managing patients with AF and had prescribed warfarin. Four subgroups of: four (4) cardiologists, (5) general physicians, (6) general practitioners (GPs) and (7) cardiology registrar-level physicians were recruited.

Data collection

Semi-structured interviews were conducted. Interview guides were developed based on existing qualitative evidence (Borg Xuereb et al., 2012). Questions to patients were open-ended focusing on their diagnosis consultation and their understanding of AF and warfarin, e.g.: Can you tell me how you got to know about your heart condition? What did you feel when you were told you needed long-term treatment (OAC)? Pilot work revealed some physicians felt uncomfortable talking about specific cases in their practice so to overcome that, scenarios extracted from the literature (Gattellari, Worthington, Zwar, & Middleton, 2008b) were used to help stimulate physicians' discussions. Questions included: Can you tell me how you would describe AF to this patient? What kinds of questions or concerns do patients often have? Interviews were digitally recorded and transcribed verbatim.

Data analysis

The principles of analysis described by Smith et al. (2009) were followed for each individual within group 1 (see Figure 1): initial coding focused on identifying what mattered to the Borg Xuereb, C., Shaw, R.L. & Lane, D. *Psychology & Health*. DOI: 10.1080/08870446.2015.1116534

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participant, noting particular language use, and signs toward subject positioning within the physician-patient consultation; interpretative coding then examined the meanings of participants' accounts in relation to the phenomenon of participatory decision-making and the physician-patient relationship. A cross-case analysis was then conducted for group 1 to generate a set of initial themes. These steps were repeated for patient groups 2-3. Themes across patient groups were then clustered. The same pattern was repeated for physician groups 4-7. A set of super-ordinate themes for patients and for physicians was generated.

Alongside this systematic process, it was necessary to engage in reflexivity within the research team to work through the meanings of concepts and interrelationships between themes (Shaw, 2010). Care was taken to retain elements of the *parts*, i.e. the perspective perceptions of the consultation and decision-making, within the *whole* of the phenomenon, i.e. the consultation itself and the concept of participatory decision-making (Smith, 2007). This was achieved through systematic comparisons of patterns, connections and relationships within and between groups.

RESULTS

Eleven patients and 16 physicians were recruited (Table 1). Themes are reported separately for patients and physicians to facilitate sense-making from these two broad perspectives.

Patients

Three super-ordinate themes were generated: Positioning within the physician-patient dyad, Health-life balance, and Drug myths and decision-making (Table 2). Each is presented in turn with exemplary data extracts.

Positioning within the physician-patient dyad

This theme explored patients' positioning of themselves within the physician-patient dyad based on their experience of the diagnostic consultation and treatment decision-making. Due to the nature of the condition, and particularly for those with asymptomatic AF, patients were Borg Xuereb, C., Shaw, R.L. & Lane, D. *Psychology & Health*. DOI: 10.1080/08870446.2015.1116534

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dependent on physicians for a diagnosis. Symptoms caused by AF were a source of anxiety for most symptomatic patients; nonetheless symptoms provided a platform for the physician to explain the diagnosis which resonated with patients' embodied experience. Labelling these previously unexplained symptoms reduced patients' distress:

I knew I had something wrong with my heart. I had told the doctor that sometimes my heart misses a beat and it didn't feel right you know. I couldn't put my finger on it you know. Of course when I came to the (consultation) they managed to diagnose it" [Katrina, Discontinued warfarin]

In asymptomatic patients, AF was often diagnosed during routine check-ups or investigations for another condition. Due to the ad hoc identification of AF, there was no underlying anxiety about symptoms which meant consultations focused on explaining the condition. In Josephine's case, the quality of her doctor's explanation signified an "excellent" relationship. Despite this, it did not result in Josephine agreeing to take warfarin:

I've got an excellent doctor and he always explains everything to you. He's told me which ventricle's not working properly. And erm... we think the TIA [mini stroke] was due to it not being able to pump the blood well from the heart so it is clotting and then the one clot just came up and gave me this TIA. [Josephine, Refused warfarin]

Patients experienced the consultation differently according to their perception of a physician's role. Some accepted a paternalistic approach while others wanted to engage in shared decision-making. David described a paternalistic consultation in which he was denied an active role. A choice was not offered to David but he described being happy to submit to his physician's expertise. This was not upsetting to David and didn't appear to threaten his ability to make his feelings known:

I was never given a choice, it was just prescribed for me, though I accept that [...] The exact words I do not remember. But I remember what I felt. I didn't feel bothered or worried about it.[...]I think that in all the years I've been with my GP or [the] clinic, I haven't had reason to

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complain. There is no one who has upset me by telling me what it is and all this business. I just leave it to them. I always make it a point to tell them HOW I FEEL. [David, Accepted warfarin]

Jonas represents a different case; although he respected the physician's expertise he wanted some degree of control to make an informed decision about treatment. The denial of this opportunity prevented him from accepting responsibility for that decision when he felt it should lie with him:

Jonas: You've got to think to yourself, well he's the mechanic, let him get on with it. Doctor said you're on warfarin, fair enough if that is his opinion... that's the way it goes.[..]I think it would have been nice to learn a bit more about it.

Interviewer: So it would have been better if they gave you some information and then you made up your decision?

Jonas: Yeah make your own decision, and then at the end of the day it's not the doctor's fault. It's your fault. [Jonas, Accepted warfarin]

Lionel further deconstructed the notion of a consultation through his experience:

Consultations aren't consultations. It is the wrong expression for what is happening. You're just told what... this is the medicine and this should be your dose. So I see you in 6 months' time. It's not a consultation; there is no interplay of patient's feelings or thoughts. [Lionel, Accepted warfarin]

For Lionel this paternalistic model and didactic approach to the consultation excluded him from the process and he stressed the importance of a two-way dialogue when making decisions about long-term treatment and health management. Lionel and Jonas positioned themselves as active participants in their consultations but that power was denied them. David was content to accept a submissive role and with that hand over the responsibility for his treatment – and possibly more widely, his health – to the experts.

Health-life balance

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Accepting warfarin as OAC therapy demands long-term medication management and lifestyle changes to ensure a therapeutic INR and appropriate warfarin dose. Changes to diet did not present particular challenges to patients, as Fiona demonstrates:

There are things that you can't eat, or have to be careful of with eating. Unfortunately that is something that I really love (laughs) like cranberries (laughs) I used to love cranberry sauce with the turkey AND BROCCOLI... but that you can live without (laughs) [Fiona, Accepted warfarin]

Although Fiona needed to give up food items she previously enjoyed, she didn't feel this was going to impact greatly on her quality of life. Regular INR monitoring (blood tests) was different and did have a significant detrimental impact on quality-of-life for some patients. Attendance at clinic proved difficult for Robert who discontinued warfarin because his employer was unsympathetic. This illustrates how control over long-term management may be out of a person's control. Furthermore, it reminds us that although AF maybe perceived as an older person's disease, as people are required to work longer there are patients of working age needing to fit chronic drug management into their existing lifestyle:

I cannot take time-off from work for monitoring. I can take time-off for other things, but not for this. It doesn't work for them. They just don't like it! [Robert, Discontinued warfarin]

For Raj, the inconvenience of regular management interfered with his lifestyle choice to travel during his retirement:

I'm retired and I like erm to spend my time going on holidays. Whilst the children were young, we couldn't afford to go away on holiday because of their education... Now we getting old and we want to try and make the most of it before it's too late [...] While we have the opportunity and good health we can do these things which we may not be able to do after, I guess. [Raj, Discontinued warfarin]

Travelling was clearly important to Raj because he had been unable to pursue these wishes when his family was young. In good health otherwise, Raj conveyed a sense of urgency to

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travel while he can before his health deteriorates in other ways. For Fiona, the clinic visits were reassuring and helped her to manage AF and its treatment. Furthermore, the emphasis for Fiona was not the need to monitor her INR at regular clinic visits but the sense of belonging she felt by being included in the long-term management of her condition:

I was transferred to a different clinic. But I asked to be transferred back to this one. I mean it's true it's a bit further away but come on, this feels like a family. They make you feel at ease. That is what you need. If you have a problem health-wise, I think that if you can be put at ease by the people who are dealing with it and your health and help you get through it. If you can be brought in as a member of a group... build a relationship, it helps. You don't feel as though you're wasting anybody's time. You don't feel as though you're another number on a piece of paper. You're part of things. People ARE taking notice and you feel like you're being cared for. [Fiona, Accepted warfarin]

For Fiona, the clinic visits were not intrusive, as they were for Raj and Robert, they helped her feel cared for, included in her treatment journey, and valued as a patient. This helped Fiona manage her health-life balance and reduced any anxiety which may have developed if she had been left without that longer term service involvement.

Drug myths and fear of stroke

Patients' perceptions of warfarin and alternative OAC drugs, e.g. aspirin, were significant for some. Aspirin is a well-known drug that is easily available over the counter, has many applications, and therefore imbued a sense of safety. Aspirin was also described by some as an 'old' drug: "*well it's old isn't it from the bark of a willow ... sort of natural thing.*" [Josephine, Refused warfarin]. This concept of a "natural" drug was associated with a healing capacity, an inability to do harm which Josephine contrasted with warfarin, which had in the past been used as rat poison:

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And it's [warfarin] such an old fashioned drug as well. It's been there for years and of course, when it first came out, everybody was 'oh it's rat poison' 'cause that is what they used to kill the rats with you see (laugh). And that sticks in a lot of people's mind, that it's rat poison.

[Josephine, Refused warfarin]

Although arguably “natural” and “old” are comparable, the ‘poisonous quality’ of warfarin superseded any other potentially positive conceptualisations for Josephine and contributed to her decision to decline it. The rat poison link didn’t prevent all patients from accepting warfarin. Although Lionel’s initial thoughts about warfarin as rat poison were not positive, he was able to reflect on the use of drugs and their different functions which enabled him to make a rational decision to accept warfarin:

I heard that it was rat poison but also used on human beings, not to kill them but keep them alive. I was unhappy, knowing it was rat poison, but in a sense all medicines are a bit of a poison aren't they.] [well it's not really poison isn't it, as it just makes them bleed, an internal bleeding. [Lionel, Accepted warfarin]

Regardless of their decision, Josephine and Lionel were able to exert control over their decision to accept or decline warfarin as OAC therapy. There was also a wish expressed to take control over their individualised risk factors for stroke which, for Jonas, worked as motivation to accept warfarin. Symptom reduction is often persuasion enough to maintain long-term treatment but for asymptomatic AF patients, that motivation is lacking. In the absence of that powerful embodied experience, patients drew upon vicarious experiences of stroke through family and friends. For Jonas, living with his mother who developed disabilities post-stroke brought to life the possibility of him experiencing the same thing. This tangible experience motivated Jonas to take control of his AF by accepting warfarin:

My mother she had a stroke. I was with mum for 17 years after she had a stroke. It's something that I wouldn't wish on anybody. Living it, with it or seeing it. She could do absolutely nothing. She could hardly speak, she got no control over any of her bodily

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functions. I wouldn't like to end up like that. If that happened to me I would ask somebody to put a gun to my head. (laughs). [Jonas, Accepted warfarin]

Patients' subjective experiences revealed a range of positions in relation to preferred consultation styles and decision-making processes. These idiosyncratic analyses have demonstrated the importance of giving patients the option to make their own choices about treatment, even if that choice is to defer to the physician's expertise or to decline treatment. Achieving a health-life balance where long-term treatment management doesn't interfere with patients' lifestyle choices needs to be considered even in the older population. Myths about particular drugs need to be addressed so preconceptions don't impede a rational decision. Especially in asymptomatic patients, the reality of the risk needs to be conveyed in order to encourage acceptance of effective OAC.

Physicians

Three super-ordinate themes were generated from physicians' accounts: Mechanised metaphors and probabilities, Navigating toward the 'right' decision, and Negotiating systemic barriers (Figure 1 & Table 2).

Mechanised metaphors and probabilities

In their attempt to be understood by patients, the physicians in this study used diagrams and metaphors to explain the nature of AF and the risks of stroke and bleeding. Physiology was assumed to be important in these explanations, as demonstrated by the diagrams used by D1, a consultant cardiologist³:

We speak in very basic terminology. Now obviously they don't know what arrhythmias is so we say there is a heart rhythm disturbance within the heart and erm and usually I do it on the basis of drawing pictures [D1, Consultant cardiologist]

³ Pseudonyms were not used for physicians as this would compromise their anonymity.
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There was clear recognition that patients would need some help digesting information imparted during consultations. D13, a GP often printed off information for patients to take home, giving them time to think about it and come back with questions if necessary:

I generally will always print something off. And it gives them an opportunity to just read something that erm... is kind of vetted by a medical professional as it were. As opposed to just going on the internet and trying to log on to some random website. And it gives them the opportunity to sort of read that, digest that, or get it read to them if they don't read English... and then come back with questions. [D13, GP]

For this GP, the use of printed material was also perceived as useful if a patient was unable to understand English. Although this offered the opportunity for relatives (or others) to translate the information it would preclude those patients' agency within the decision-making process and demand the involvement of a third party whether that was their preference or not. An example metaphor, used by a GP in this example (D15), was "wiring". This mechanised metaphor focused on the physiology of the body but also drew upon the functional meanings of electricity to help convey the potential danger if AF were not treated appropriately:

I would explain to them that they have an irregular heart and their heart is going irregularly, and I usually sort of tap it out for them as to what is happening. I tell them that the electrical wiring of the heart is erm still there and fine but like any wiring in an old house. You know the insulation is just got a bit worn. So the currents tend to short-circuit and not connect up. That is a sort of analogy for the patients. And erm... that erm in the short term they are not in any risk but we need to get it sorted out. [D15, GP]

This analogy was intended to improve patient understanding of the need for treatment. It also worked on another level: it is a metaphor of an electrical system hidden inside the walls of a house; similarly, the faulty "wiring" of the heart is not visible, and for asymptomatic patients, there is no bodily awareness of it. Almost all consultant cardiologists and cardiology registrars

in this sample attempted to convey the reality of risks to patients using probabilities. This assumed an understanding of varying grades of probability, for example:

Your risk of getting a stroke based on what we know... is going to be 7-8%. If I put you on aspirin I'll bring you down to 4-5%... which is still quite high, higher than the average population. But if you start warfarin, you bring it down to 2-3% which is only slightly higher than someone at the same age. [D8, Cardiology registrar]

This explanation is quite complex, involving several risk levels that are contingent upon the treatment decision. There was clear recognition of the need to communicate clearly to patients which led to creative explanations. However, those explanations remained focused on physiology and risk levels. Concerns about long-term management and clinic appointments or perceptions of drugs were not addressed.

Navigating toward the 'right' decision

Among the range of physicians interviewed a desire to achieve concordance and involve patients in the decision-making process was expressed. Physicians set out to achieve this through information provision and negotiation but soon fell back into a position of advice-giving when it came to decision-making:

The only way you can empower the patient to make decisions is to provide the information that they require to make that decision. AND if you don't then they make the decision on the basis on inaccurate or inadequate information and they often come to the wrong conclusion. Erm whereas if you provide them with a balanced argument, it erm... essentially you give your best advice to the patient and then it's their decision to make, but it's important for you to provide them with that information. But often times the majority of my patients leave it to me to decide okay. I still give them information so that they understand the decision making that I am erm... erm I'm making but erm the majority just allows me to choose what's best for them. [D1, Consultant cardiologist]

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In this example from D1 there is a well-meant intention to engage and empower patients in the decision-making. However, there is also an assumption that patients are unable to gather the ‘right’ information for themselves which makes them dependent on medical expertise (to avoid the “wrong conclusion”). It is difficult to determine from this extract whether D1 asserts authority in decision-making or whether patients do indeed submit of their own accord. We know from patients’ accounts that some are happy to defer to physician expertise. This is not surprising however, given the frame of reference offered by physicians is physiology and risk levels. If physicians explored patients’ frames of reference, such as perceptions of “old” drugs or impracticalities of regular clinic visits, patients may in turn develop an authentic sense of empowerment to make a decision on their own terms.

To achieve the ‘right’ treatment decision, i.e. the most effective drug based on scientific evidence, D3, a consultant cardiologist, admitted to leaving information about risks out. Above we saw physicians’ explanations of the need to reduce stroke risk levels; in this example, D3 avoided discussing the counter risk of bleeding:

I don’t usually warn them about brain haemorrhage... perhaps I should. But I don’t. [D3, Consultant cardiologist]

Indeed, several physicians described capitalising on the known fear of stroke, found in the patient sample, to persuade patients to make the ‘right’ choice:

I mean generally, if you tell them it’s a stroke, they get worried about it and generally as you know, when people think of stroke, they think ‘oh my god, I’ll become bed bound, very disabled, I wouldn’t be able to do it’. So they start to take it very seriously that AF is not as benign as they expected. [D10, General physician]

The issue of regular INR monitoring was raised by physicians from the perspective of whether they felt the patient was likely to adhere to long-term treatment management. D8, a cardiology

registrar, introduced the notion of responsibility in relation to treatment adherence which was identified as a contributing factor in patients' decision-making processes:

So with warfarin it is something that you need to have a shared responsibility. 'Cause you cannot go chasing the patient... you need your INR checked today. The patient needs to have some motivation. [D8, Cardiology registrar]

The view expressed is that management of AF and monitoring of INR is a shared responsibility but in the second half of this extract D8 revealed that the onus is on the patient to undertake that monitoring independently. Thus, within the navigation toward the 'right' decision, there was some acknowledgement that accepting warfarin as OAC demanded a significant commitment from the patient.

Negotiating systemic barriers

Physicians were aware of the need for better ways to inform patients about AF and OAC. The amount of time available in consultations was seen as the biggest obstacle to achieving that. This was particularly true for physicians in hospital clinics:

Patient education is very important, but it is one that we do badly, because there isn't enough time. In general I see about 15 to 16 patients in 3 hours... so there is not enough time to talk about AF, talk about what you're gonna do... and start talking about warfarin and then educate patients as well. [D8, Cardiology registrar]

By comparison, the GPs interviewed felt that time spent with patients was more flexible and could be extended if necessary. As D14 indicates, this meant GPs were able to establish a rapport with patients and follow-up concerns once patients had had time to contemplate information provided and issues discussed. There was recognition that a diagnosis of AF with the need for life-long OAC constituted "profound news" (D13, GP) and so would require more than one discussion:

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Time...you don't have as much time with the patient as you would like..... In general practice at least I could tell them we don't have much time right now, but we can meet again next week and chat about it in more detail, so the follow-up time is much shorter than with hospital. I could see the same patient every day if I wanted to. [D14, GP]

It also meant that information overload at the initial consultation was avoided. One GP clearly understood the impact of a diagnosis of AF on patients:

I'm sure that if they walk out the door and see someone else and asks them, so what did the physician say, they would say, my heart is beating irregularly, I don't remember anything else. So you again, you're telling them some profound news which they may or may not be expecting. [D13, GP]

The idea of multiple GP consultations, knowledge of their patients' social histories and support systems were the envy of hospital physicians like D8. Further support for the primary care setting as a facilitator of good physician-patient relationships was provided by D16:

In our chronic disease clinics... the people with AF on warfarin will see the same practitioner.....it's a very good system... helps build a very good relationship [...] I know how they live, where they live, their family members, what support system they have got. As well as the medical history I know their social history. [D16, GP]

However, primary care also faced some challenges. Although GPs had experience of prescribing warfarin, patients were usually referred to secondary care for AF diagnosis which meant the decision to initiate warfarin was often taken by secondary care. Furthermore, a general physician, D9, raised the issue of general versus specialist knowledge: for general physicians, knowledge and use of disease-specific guidelines was more challenging than for cardiologists. D9 raised the issue that physicians with different specialisms need targeted guidelines to help them make decisions about specific cases in practice that invariably do not match the 'average' patient described in the guidelines:

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Well it's by education, by making guidelines simpler and easy to use and by stratifying the guidelines, there should be one A4 page for an emergency department medical assessment unit, a different A4 for cardiology clinics, different A4 for general practice, and different one for general physicians. All probably saying the same thing, but the way it is being put across, the simplicity is the important point. [D9, General physician]

Physician accounts revealed efforts to communicate clearly to patients but their own perceptions of what is significant in a treatment decision may have influenced the content of their consultation and directed it away from what is important to patients. It was clear that physicians used the evidence-base to determine the 'right' decision regarding treatment. Although they aimed to involve patients, some defaulted to their expert advice-giving mode. In addition, there were a number of systemic barriers to the development of rapport in secondary care which precluded the development of a good relationship and prevented detailed discussions to confirm understanding of AF and to compare different treatment options. Primary care offered the luxury of time but not the specialist knowledge.

DISCUSSION

This multi-perspective design has enabled in-depth analyses of subjective experiences of AF consultations and OAC decision-making. Interpretative analysis of accounts from different perspectives has generated meaning-led descriptions of parts of the phenomenon as it was experienced by different groups. The focus of patients' accounts was that a consultation should be *an opportunity to make an informed decision* and *they would like the tools to do that within the context of their lived experience*, i.e. what concerned them. For patients, the consultation offered a range of experiences from open dialogue to closed decisions to which they were subjected and there were varying degrees of satisfaction with this. For physicians the consultation was *an opportunity to ensure the patient received the best treatment* according to good practice guidance. For them, the consultation demanded communication skills and

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creativity in conveying messages, the ability to create for patients a sense of empowerment, and the opportunity to steer patients toward the ‘right’ decision.

When we put these descriptions together, different meanings and functions of the consultation were evident. By converging these multi-perspective descriptions we were able to create a ‘Gestalt’ description (where the sum is bigger than its parts) of the consultation as: *an open space* where patients are offered accessible information and time for consideration; an opportunity for physicians to determine *what matters to patients within their life context* when making a treatment decision; a *collaborative consideration of options* taking into account the evidence base and what is right for the patient; and a *two-way dialogue* where physicians adopt *academic humility* and *patients feel genuinely confident* to make an informed decision that is right for them. This experience-focused analysis of the consultation has produced a description that is not far off the proposal of concordance (Horne et al., 2005). However, for some patients this remained an ideal; changes in practice are required for the concepts of participatory decision-making and concordance to become a reality.

Physicians in this study were concerned about effective delivery of information and used diagrams and metaphors to achieve that. Previous research has confirmed that a combination of written, oral, and pictorial information is most effective (Watson & McKinstry, 2009; Fuller et al, 2004). A recent intensive educational intervention (the TREAT study; Clarkesmith, Pattison, Lip, & Lane, 2013) combined different modes of information delivery using an educational booklet, DVD, worksheets, patient diary and ‘expert’ patient narratives, and significantly improved INR management in the first six months for newly-diagnosed AF patients initiating warfarin. However, concerns about follow-up and long-term drug management raised by patients in this study confirm previous findings (Clarkesmith et al.,

2013; Mazor et al., 2007) that on-going educational support is critical to reinforce and remind patients of key information; something that may not currently occur in clinical practice.

One physician described the diagnostic consultation as an occasion delivering “profound news”. This raises concerns about how much information patients remember which supports previous findings that patients have gaps in understanding and recall following consultations and that knowledge acquisition does not necessarily translate to understanding; it is multi-faceted and may require future educational sessions (Lane et al., 2015a). Lack of understanding and recollection reduces patient satisfaction and commitment to treatment (Watson & McKinstry, 2009). Recall is also affected by the use of medical terminology, patients’ level of education, and it declines with age (Safeer & Keenan, 2005; Watson & McKinstry, 2009). Again, this suggests a need for on-going support for patients following diagnosis, which may improve patient experience (feeling cared for) as well as improving treatment adherence. In addition, it suggests a need for physicians not only to adopt creative ways of conveying information in plain language but this study also suggests that tailoring the content of that information around what matters to the patient may improve satisfaction with treatment decisions.

Clinical guidelines advocate inclusion of patient values and preferences in OAC treatment decisions (NICE, 2014; Camm et al., 2012). However, most patients perceived that physicians took a paternalistic approach to decision-making, sometimes despite intentions to include the patient. This supports earlier research which suggested that clinicians’ attempts to engage patients in decision-making may unintentionally coerce patients to submit to the clinicians’ perspective (Waterworth & Luker, 1990). The reasons why some patients were content to submit to the physician may be related to lack of awareness of such coercion or it may be an expression of discomfort with demands on patients to take responsibility for their healthcare

decisions. Previously, responsibility for diagnosis and treatment lay with physicians. Indeed, Parsons' (1951) classic description of the 'sick role' emphasised the need for illness to be sanctioned by a doctor. Since the advocacy of patient choice in the UK National Health Service (NHS)⁴, an expectation of patient involvement and participatory decision-making has become commonplace, yet this study suggests both patients and physicians are still not totally comfortable with it and are unsure of what it should look like in practice.

Lack of adequate time within consultations was identified as a systemic barrier, especially in secondary care, to establishing the level of rapport required for genuine patient involvement to occur, confirming previous quantitative (Williams & Calnan, 1991) and qualitative (Borg Xuereb et al., 2012) research. Furthermore, research from some decades ago concluded that patients and physicians have different conceptualisations of clinical encounters (Mishler, 1984) and this research supports findings that patients make sense of their clinical experience in the context of their own views and beliefs (Williams & Calnan, 1991). Patient stories about refusing warfarin demonstrate that lifestyle needs and choices were significant to their decision. Yet physicians' information provision focused on explaining the physiology of the condition and the stroke risk reduction associated with warfarin.

Taking a phenomenological approach to this research has enabled in-depth analyses of the subjective meanings individuals attribute to their experiences and has prioritised the description of how the phenomenon of the diagnostic consultation appears to individuals coming at it from different perspectives. By doing this we have been able to foreground patients' and physicians' conceptualisations of consultations and participatory decision-making in our attempt to understand them. The analytic conclusion that a consultation should constitute an open space

⁴ See for example the NHS Choices website: <http://www.nhs.uk/CHOICEINTHENHS/Pages/Choicehome.aspx> (accessed 31/07/15).

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for two-way dialogue, where what matters to the patient is prioritised, involving a collaborative consideration of options, where physicians are humble about the evidence base in respect of a patient's life context and where patients feel genuinely confident to make an informed decision resonates with Walseth & Schei's (2011) adoption of Habermas' (1984) theory of communicative action as a tool in medical lifestyle interventions. We know that trust is important in establishing a concordant consultation style (Pullon, McKinlay, Stubbe, Todd, & Badenhorst, 2011). Walseth & Schei (2011) also stipulated the need for empathy, caring, and seeing the patient as a person rather than a medical object, which echoes the current findings and previous constructions of interpretative approaches to the physician-patient relationship and to decision-making (Horne et al., 2005; Emmanuel & Emmanuel, 1992). For Walseth & Schei (2011: 81), the focus of healthcare consultations should rest with the patient:

Decisions should spring from a respectful dialogue concerning patients' commitments, feelings and practical circumstances, sharing reflections concerning what is right, what is good and what is practically feasible for the patient; conversations where the world of everyday life is given language and reflected upon.

This definition powerfully represents the findings of this study and confirms the need to include within the consultation discussions about the patient's life context as well as issues related to drug efficacy and the risks associated with different treatment options. To achieve this, Walseth & Scheir (2011) turned to Habermas' (1984) notion of communicative rationality: fundamentally, Habermas proposed that decisions involving human beings require a lifeworld perspective, i.e., an approach which foregrounds human experience within its relational, cultural and historical context. Mishler (1984) also connected Habermas' ideas to the context of a medical consultation and recognised, as this study has done, that patients and physicians find themselves in the midst of the colliding systems of the lifeworld and the system world.

Nevertheless, Walseth & Schei (2011) argue that Habermas' theory of communicative action offers a concrete approach for constructing a dialogue that observes the rules and norms of communicative rationality within the worlds of the individual and the system. This involves including three dimensions within a consultation: *The objective world*: medical evidence regarding best treatment, prevalence, risk; *what is feasible*; *The social world*: a patient's family context, significant relationships, socio-economic status; *what is right for the patient*; *The subjective world*: a patient's intentions, thoughts, wishes, physical needs, requiring an empathic consultation to enable a truthful representation of patients' needs; *what is good for the patient*.

This proposed content for medical consultations, according to Walseth & Schei (2011), would create an environment conducive to participatory decision-making. The findings of the current study support this case. There was a readiness among physicians to ensure patient engagement and understanding but their arguments were couched very firmly within the objective world of medical fact. By contrast, patients' decisions were informed by their lifestyle choices, i.e., their social and subjective worlds. Areas of overlap between accounts included risk of stroke, confirming that we should not go so far down the line of satisfying patients' desires that we forget the need to consider the medical risks to patients of different treatment decisions. However, framing the consideration of treatment options within all three dimensions would create binding and justified decisions (Habermas, 1997) which may help to improve both patient satisfaction and adherence to treatment because their health and healthcare management decisions were made against the backdrop of their own life context.

The biggest barriers to implementing this approach are systemic: referral to secondary care where time is limited; the luxury of time in primary care (through repeated consultations) is not always accompanied by appropriate specialist knowledge due to the generalist approach in general practice. Previous effective initiatives in overcoming such barriers are: the use of Borg Xuereb, C., Shaw, R.L. & Lane, D. *Psychology & Health*. DOI: 10.1080/08870446.2015.1116534

multidisciplinary teams perhaps with specialist nurses (Hendriks et al., 2012); the use of new technologies (LaHaye et al., 2014); multifaceted interventions (Clarkesmith et al., 2013); and more flexible practice management (Wilson & Childs, 2002). It is conceivable that the use of multidisciplinary teams and specialist nurses in a more flexibly organised primary care setting (following existing approaches to care for e.g., diabetes, asthma) would support the inclusion of Walseth & Schei's (2011) three dimensions within consultations and would help foster rapport over time to help support patients' long-term drug management with follow-up appointments. In addition, the use of multifaceted interventions would maximise patient understanding (Watson & McKinstry, 2009; Fuller et al., 2004).

This study represents a significant development in phenomenological design and offered a large sample, made up of small subsamples, for an IPA study (Smith et al., 2009). The benefits of this multi-perspective approach have been outlined. There is more work to be done, however. This is a new methodological design which is challenging from a practical point of view and which demands further theoretical work to fully appreciate its contribution to applied phenomenological health research. One way this could be achieved is through combining an interpretative phenomenological approach which focuses on an idiographic analysis of people's experiences of a phenomenon with a descriptive (or transcendental) phenomenological analysis of the phenomenon itself in order to create an essential description of the phenomenon and perspective accounts of how it appears to different people in their consciousness. This would constitute a pluralist approach because IPA and descriptive phenomenology are considered methods in their own right (e.g., Langdridge, 2007). Pluralist methods have been shown to offer enlightening interpretations of the same phenomenon by adopting different positions to the unit of analysis and by examining the phenomenon using different interpretative lenses (Frost, 2011). Further applied research using recordings of

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consultations and reflective interviews following them would help develop our understanding of what happens within the consultation and different perspectives of it.

CONCLUSION

This qualitative study used an innovative multi-perspective IPA design to make sense of patients' and physicians' experiences of consultations about AF and OAC decision-making. Findings highlight the need for physicians and patients to become more comfortable and confident in engaging in participatory decision-making. Inclusion of three dimensions – the objective, social and subjective worlds – within a consultation would ensure discussions include medical evidence but also the life context for patients to ensure treatment decisions are feasible, right, and good for the patient. Using multidisciplinary teams and multifaceted information provision may help create an environment conducive to genuine patient involvement.

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Figure 1: Multi-perspective analytic procedure

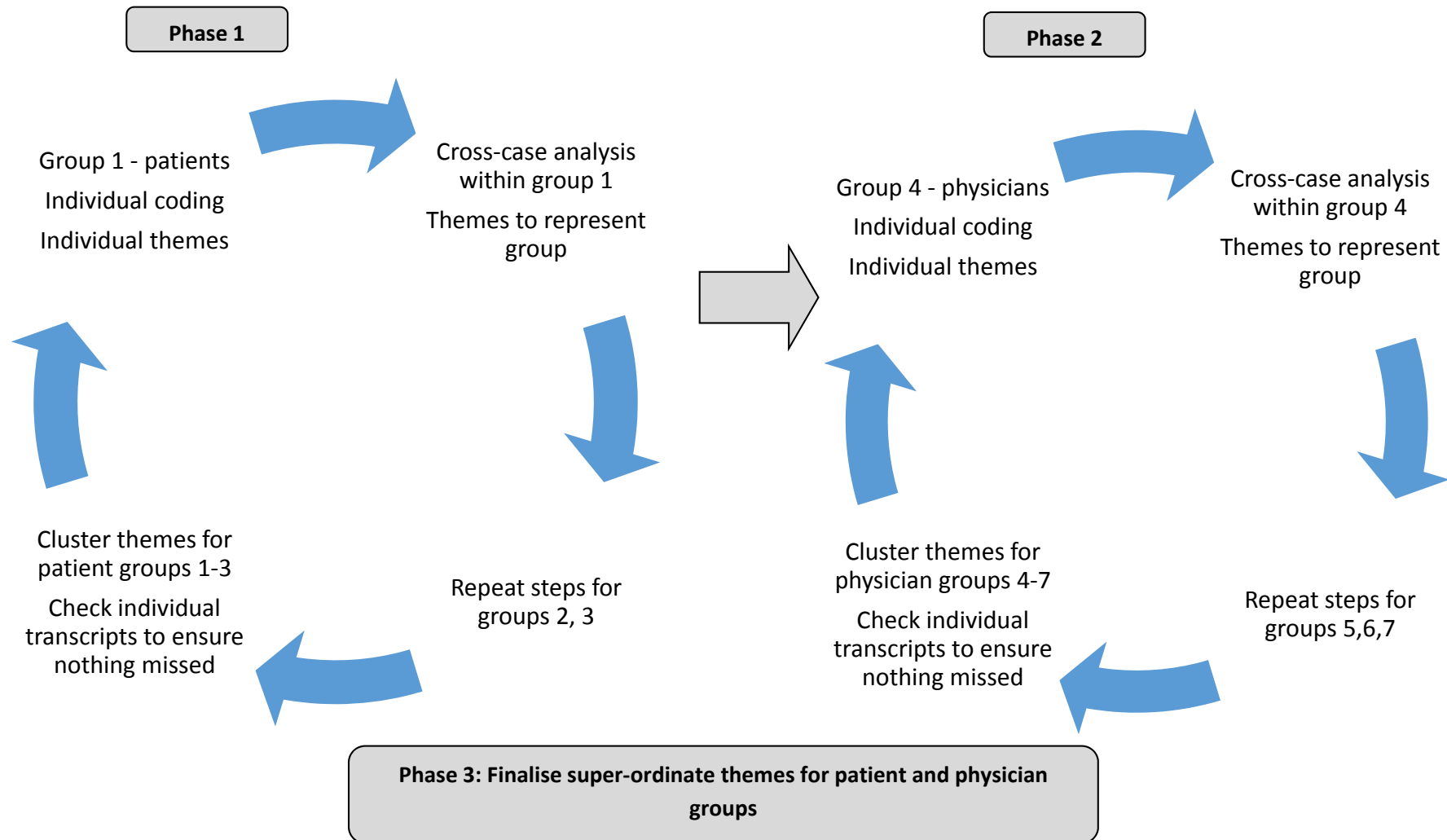


Table 1: Patient and physician characteristics

Patients				Physicians ⁵		
Pseudonym	Age	Gender	Ethnicity	Physician code	Age	Years at specialty level
Accepted warfarin				Consultant Cardiologists		
Lionel	78	Male	White	D1	39	4
Jonas	67	Male	White	D2	45	20
Fiona	70	Female	White	D3	50	24
David	83	Male	White	D4	44	10
Refused warfarin				Cardiology Registrars		
Will	69	Male	White	D5	35	5
Greg	53	Male	White	D6	33	4
Josephine	58	Female	White	D7	32	6
Shona	77	Female	African-Caribbean	D8	37	6
Discontinued warfarin				Consultant General Physicians		
Katrina	80	Female	White	D9	48	7
Raj	72	Male	South-Asian	D10	46	9
Robert	71	Male	White	D11	39	4
				D12	42	9
				General Practitioners		
				D13	40	12
				D14	40	11
				D15	60	31
				D16	37	9

⁵ Demographic details of physician participants are not included because revealing that information could compromise their anonymity.
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Table 2: Super-ordinate themes generated

Patients	Physicians
<p><i>Positioning within the patient-physician dyad</i></p> <ul style="list-style-type: none"> • Patients are dependent on physicians for a diagnosis • Reported lack of choice & desire for choice in treatment decision • Negotiation of responsibility in the decision • Consultations are didactic not dialogic 	<p><i>Mechanised metaphors and probabilities</i></p> <ul style="list-style-type: none"> • Analogies of machines to help descriptions of AF • Probabilities of risks of stroke and bleeding dominate
<p><i>Health-life balance</i></p> <ul style="list-style-type: none"> • Fitting warfarin into life rather than vice versa • Unable to meet demands of regular life-long monitoring • Monitoring as a form of care and anxiety reduction 	<p><i>Navigating toward the ‘right’ decision</i></p> <ul style="list-style-type: none"> • Physicians own the ‘right’ decision • Genuine aim for concordance but overtaken by ingrained paternalism
<p><i>Drug myths and fear of stroke</i></p> <ul style="list-style-type: none"> • Warfarin is old fashioned versus aspirin as aged wisdom • Warfarin as rat poison versus all drugs are poisonous • Fear of stroke as motivation for treatment 	<p><i>Negotiating systemic barriers</i></p> <ul style="list-style-type: none"> • Time restraints prevent detailed information provision and discussion • No time for patients to think in secondary care • Luxury of repeated consultations and rapport-building in primary care • Increased expertise but lack of time in secondary care