

Draft AFIB Report

Understanding Patient Perspectives on Stroke Prevention Therapy Decisions in Atrial Fibrillation

Introduction

This Patient and Community Engagement Research (PaCER) qualitative research study is the patient perspective component of Patient And Clinician Perspectives on AF Stroke Prevention Decisions, the first project in a linked three part project whose goal is the design of shared decision-making aids for stroke prevention. The decision-making aids would be used collaboratively and interactively within the Atrial Fibrillation (AF) clinic by physicians and patients to guide the selection of stroke reduction medication that best suits each individual patient's needs.

Atrial fibrillation (AF) is a common heart rhythm problem that increases the risk of stroke. Several effective therapies can reduce stroke risk, but they remain underused in the community. The Calgary AF Clinic provides comprehensive AF care and education, but patient's experiences with selecting antithrombotic therapy have not been studied. Understanding patient perspectives is critical to the development of an interactive, computerized patient decision aid to support shared decision-making in the AF Clinic. This study, using PaCER research methods, will ensure that the new decision making tools are designed with the consideration of the patients' collective experiences, perspectives and goals. All of the researchers in this study are specially trained patients with chronic diseases, which entail making personal choices about preventative and treatment medications.

Background and Context

As always before and during the research project, PaCER researchers undertook a literature review to find any previous literature published about the topic being researched. We found a limited number of articles relating to patient decision making about anticoagulant medication for patients with atrial fibrillation. This may be linked to length of time the newer drugs have been available. Some anticoagulant medication studies focus on patient and physician threshold for bleeds (Alonso-Coello, Montori et al., 2014; Lane & Lip, 2014) while others focused on patients' perceived benefits and risks as well a cost of the medication.(Moia, Mantovani et al., 2013; Mehdi, Gagne et al, 2013).

Methods

PaCER uses several qualitative research methods set within the patient engagement research framework outlined in *Grey Matters* (Marlett & Emes, 2010) For this study we chose grounded theory (Glaser & Strauss, 1967) as we wanted to understand the patient experiences and beliefs in the hope of developing some theory around how AF patients made decisions about stroke prevention medication

Recruitment and Inclusion Criteria

We used purposive sampling of patients who had visited to AF Clinic within the last twelve months, were over age 18 and were able to speak English well enough to participate in focus groups or interviews. Each prospective participant was interviewed by telephone by a research team member to ensure that they fitted the criteria and understood the parameters of the study.

Participants

We recruited 30 participants (18 males), all of whom had attended the AF Clinic within the last year. We facilitated one SET group (3 participants), three Collect groups (7,7,6 participants respectively), one Reflect group (9 returning participants) and interviewed 7 patients.

Demographic Information

Code #	Gender	Age	Level of Education	Job Status	First Language	Country of origin	Age at Onset
S1	F	49	High School	NW	English	Canada	39
S2	M	46	Univ Grad	FT	English	Canada	38
S3	F	70	High School	RTD	English	Canada	66
C1	M	68	Trade School	PT	English	Holland	60
C2	M	57	Univ Grad	FT	English	Canada	53
C3	F	82	High School	RTD	Dutch	Holland	71
C4	F	66	College	RTD	French	Canada	63
C5	F	61	Tech Cert	FT	English	Canada	58
C6	M	60	Univ Grad	NW	English	Canada	54
C7	M	75	Univ Grad	RTD	Punjabi	India	70
C8	M	69	College	FT	English	UK	67
C9	M	67	High School	FT	German	Germany	50
C10	M	63	Univ Grad	PT	English	Canada	57
C11	M	49	College	FT	English	Canada	37
C12	M	65	Tech College	RTD	English	Canada	63
C13	F	57	HS	Med Leave	English	Canada	55
C14	F	61	College	FT	English	Canada	50
C15	F	74	BScN	RTD	English	Canada	63

C16	F	69	College	RTD	Mandarin	China	65
C17	M	79	Univ Grad	RTD	German	Germany	57
C18	F	82	College	RTD	English	Canada	79
C19	M	62	Univ Grad	RTD	English	Canada	59
C20	M	69	Univ Grad	RTD	English	Canada	56
C21	M	70	Tech College	RTD	English	Canada	67
C22	M	62	BSc	PT	English	Canada	59
C23	M	67	Tech College	RTD	English	Canada	57

Note: 4 interview participants did not return demographic information.

Data Collection and Analysis

We collected data using the PaCER framework, which consists of three phases: SET, COLLECT and REFLECT.

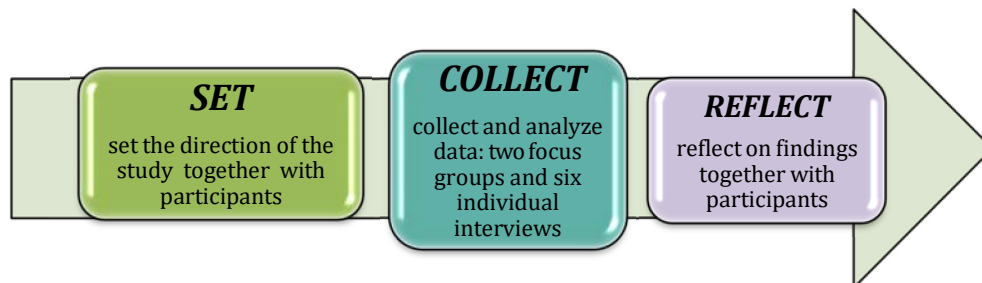


Figure 1. PaCER Research Method

Our patient engagement research process is iterative and amenable to changes in direction depending on the information received from any group (Marlett, Shklarov et al., 2014). The Set group is used to indicate what topics are of the highest importance to the patient participants and directs the guiding questions for the first Collect group. Information from each subsequent Collect group or interview is used to inform the guiding questions for the next group or interview. However, each group or interview participant was asked the same initial question: *Please tell us about your experience with AF and how you made your anticoagulant medication decisions.* This opened the door for participants to describe their experiences. We encouraged discussion among the participants and only used short prompt questions to deepen the information being given. PaCER uses 3 facilitators; one to facilitate the discussion, one to take flip chart notes and one to do a process recording. All groups and interviews are audio recorded and later transcribed. All three recording methods are used in the analysis.

Set Group

Our Set group had three participants. Despite the small number, the group lasted for the full five hours as all three participants discussed their experiences in detail. In keeping with PaCER protocol we used the flip chart notes to develop the guiding questions for the first Collect group. The flip chart notes were posted on the walls and the three participants were asked to check the veracity of the notes and were invited to give additional comments on all of the noted topics as well as identifying any omissions.

Topics of major importance to our participants used to formulate guiding question for the first Collect group were:

- *Any medication, whether for treatment of AF or to prevent stroke, must fit with the patients' beliefs about medication.*
- *Medication must fit in with the patients' chosen lifestyles.*
- *Patients wanted more information about medications from their physicians and the AF clinic*
- *Patients needed time to consider medication choices.*

Collect Groups and Interviews

We held three Collect focus groups with six, seven and seven participants respectively, all lasting for the full five hours. All three were analyzed iteratively and although we reached saturation of themes and sub themes at the end of group two we decided to go ahead with a third group and seven narrative interviews to be sure we had rich and thick data to inform the subsequent phases of the overall project.

Reflect Group

We had nine returning participants for the Reflect group. With full patient consent, we invited the Principal Investigator and one of his graduate students for the afternoon discussion session.

In the morning session participants reviewed the themes and subthemes the PaCER researchers had identified emerging from the data gained during the Set focus group and the Collect focus groups and interviews. Posters outlining 13 major themes and 16 subthemes analyzed from the data using participatory grounded theory (Gillard & Simons, 2012; Taram, Schacter & Stalker, 2005) were displayed on the walls. Each poster named the theme/subtheme, an explanation of the theme or subtheme and several verbatim quotes to illustrate the theme or subtheme. Participants were given clipboards with comment sheets and asked to go round all of the posters making notes on

as many as they liked. They could disagree, agree with the information as well as add comments and experiences within any given theme or subtheme. They were asked to fix a coloured sticky note to the poster if they had made a comment, allowing us to see which themes and sub themes were most popular and therefore most important to our participants. This allowed participants to check our analysis, challenge or add to it, and allowed for the emergence of theory based on the data during the afternoon discussion.

Research Credibility and Trustworthiness

We used several strategies to raise the credibility and trustworthiness of the research: (1) The patient researchers facilitating the groups, interviewing patients and analyzing the data had to understand, reflect on, and state his/her biases (Bogdan & Taylor, 1975; Kirk & Muller, 1975; Patton, 1990) (2) As patients we had a familiarity with the experiences of the participants (Shenton, 2004). (3) We used research colleagues, academic supervisors from PaCER, and peers to review and discuss the emerging data, coding, and themes (Lincoln & Guba, 1986, Shenton, 2004). (4) We used member checks (Reflect group) to ensure the accuracy of our analysis. (5) We employed iterative questioning, triangulation (e.g., using a combination of methods – grounded theory, participatory grounded theory, and content analysis, as well as two different data collection techniques), and thick description of AF patient experiences Lincoln & Guba, 1986, Patton, 1990). (6) We completed a literature review to assess the congruence of our findings with previous research (Berg, 1989; Lincoln & Guba, 1986; Morse et al., 2002; Shenton, 2004). (7) Patient to patient research lessens the reflexivity present when traditional healthcare providers are used (Berger, 2015).

Results

The results section is divided into three parts; A) an analysis of the responses participants gave when directly asked how they made decisions about anti stroke medications, B) the findings about decision making that emerged from the analysis of the discussions about their AF diagnosis and their experiences since diagnosis and C) the articulation of a emerging theory based on what appeared to most important to the participants with respect to their AF diagnosis and the increased possibility of stroke.

A) Stated Participant Reasons for Choosing, Continuing or Stopping a Medication

- I. Fits life style
- II. Information patients given or researched
- III. Tolerance for medication
- IV. Cost
- V. It works for me
- VI. Perceived pressure

- I. Participants often made anti-coagulant drug choices based on how they lived their lives and the activities they enjoyed. Those who continued to pursue their back country activities did not want to risk a bleed, while others indicated that they simply did not have time to go for the lab tests necessary when taking Warfarin. It appeared that some patients who had chosen not to take Warfarin because of the lab tests were unaware that there were other medications without lab testing they could choose.

Theme	Exemplar Quotes
Fits Life Style	<p>596) <i>I am on aspirin as an anti-coagulant. Again, because of my active lifestyle, I choose not to go the Warfarin route as I do not wish to bleed in the mountains. Aspirin is the best-worst choice for that</i></p> <p>605) <i>Plavix is not the right choice for me. It is better than Aspirin, but unless I have any issues, I don't want to move there. Plavix is a good drug but it has a higher risk of bleeds and with my active lifestyle, it might not be the best choice.</i></p> <p>634) <i>They wanted me to go to Warfarin but I wouldn't (too many tests). I came out on Innohep</i></p> <p>728)-<i>I have heard with Warfarin, because you have to go for tests so many times, to me that is curbing my life experiences, because I am very active and think I don't have time to do this. -Is there another option? Warfarin was up there strongly up front and centre.</i></p> <p>2-528y) <i>Warfarin; don't like to go to lab every 7 weeks for tests; now off Warfarin</i></p> <p>835) <i>I was elated when that option came up (Pradaxa) because I'd been on Warfarin for ten years so going through the lab 2-3 times a month.</i></p> <p>E048) <i>With the Warfarin it was unsettling because you had to go every three weeks (lab tests)...it was some anxiety but with the Eliquis it's fine.</i></p>

- II. Participants made their decisions based on information they were given or had researched. While many patients preferred to research any drug the physicians had recommended others said they simply took what had been recommended even if they were less than happy and would have liked more information.

Theme	Exemplar Quotes
Information patients given or researched	<p>725) <i>I did go to the pharmacy class which did explain everything and was very good and helpful. They went through all the options. But that was 18 months after I'd been diagnosed. It does explain some things, but it is still</i></p>

	<p><i>vague because what works for you, does not work for you and so on.</i></p> <p><i>908) They sent the prescription (Metropolol) over to my doctor and that is what he prescribed... I also take 81mg low dose aspirin in the morning...</i></p> <p><i>644) So I said to my family doctor, "Something is killing me. And the only thing that I'm doing is taking an injection in my abdomen. And when I did my research on it, "This is in a high sulfide solution and I am very sensitive to sulfide. So we switched from Pradaxa to Eliquis.</i></p> <p><i>1028)...I don't know how he (cardiologist) comes up with the answers. That is important to me.</i></p> <p><i>1009) I found out I just have to make sure that I'm not doing things that would give me a heavy bleed...You have to think before you choose something...</i></p> <p><i>E018) He did give me choices of drugs but he did recommend what would work best for me.</i></p> <p><i>724) I'm still frustrated, confused that I'm being offered stuff that I don't know anything about.</i></p>
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III. Many participants found that they had adverse side effects when they took the medication prescribed to prevent stroke. Some chose to try other drugs, some opted for Aspirin but others chose not to take any anti coagulant medication.

Theme	Exemplar Quote
Tolerance for medication	<p><i>1063) There are so many side effects, is it worth being on the medications?</i></p> <p><i>2-732) this blood thinner thing really upset me, bothers me (risk of bleeding)-Because it affects other health issues-Yet if I stop taking it...you can get a stroke...</i></p> <p><i>834) Lots of GI issues,(with Pradaxa) chronic diarrhea...That was the big one.</i></p> <p><i>836) The reaction I had to Warfarin is that it dried my eyelids out so my eyelids would crack and bleed all the time.</i></p> <p><i>2-633) The doctor suggested another medication I took it but I got reaction...I didn't try another one I said I am going to take baby aspirin...The doctor at AF Clinic said: if you want to take baby aspirin that is your choice because if you get stroke that is your choice...</i></p> <p><i>159) I did start taking baby aspirin. I had to stop that. It gave me severe tinnitus so I just stopped and it went away immediately. So I'm like okay, I'm not going to debate that</i></p>

	<p><i>too much.</i></p> <p><i>958) they also want me to take Lipitor...I was surprised that they wanted a skinny guy like me to take Lipitor...I not happy with this...the number of side effects... the doctors don't realize the power that they may or may not have... you walk away (from doctor's office) and try to figure out what was important...it (Lipitor) doesn't stop stroke.</i></p>
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IV. Cost of the medication prescribed was a factor in many patients' decision making process, especially for those without insurance coverage.

Theme	Exemplar Quotes
Cost	<p><i>2-685)-yes (cost is an issue) I am in a fixed income... My prescription bill is \$1.700 a year...-Pradaxa is 50% of that.-If I can get less dosage and cut it down from \$100 to \$50...It seems the doctor just recommend a blanket dosage...</i></p> <p><i>879) My doctor at the time...he told me, you know that you have the insurance for it why don't you take Pradaxa? So I changed over to Pradaxa.</i></p> <p><i>E046) It (Pradaxa) was brought up in class but it was at the time when you had to pay for it so they said if the Warfarin was working, and it was at the time, just stay on it. With the Eliquis, it's very expensive but because I'm a senior now the max I pay is \$25.</i></p> <p><i>2-678) I am wondering how do you get someone to re-examining the medication you are on if they have it changed or whatever...like Pradaxa is very expensive it costs \$100 a month...</i></p> <p><i>871) Before Pradaxa I took Warfarin and it seemed to be okay. It didn't bother me but I have good insurance so I went to the Pradaxa because you don't have to worry about anything.</i></p>

V. None of the participants in this study had had a stroke so most believed that whatever they were doing was working for them. Many stressed the importance of "listening to their bodies" doing whatever felt best for them no matter what may have been prescribed. These were the people who were happy with their choices.

Theme	Exemplar Quote
If it works for me	<i>680) How long should it take for me to say if it is working</i>

	<p><i>or not? I also have made a choice that I want quality of life today. I don't care about quantity. When we switch medications, I'd say to my doctor I am trying this for (I'd ask how long before it should start working), and I'd say, I'll try this for x number of months or weeks, and after that, if it is not working for me (doesn't feel good), it is gone.</i></p> <p><i>1266) If I don't feel that a certain drug is good for me I talk it over with my doctor or don't take it and try to get something else... I think that self-consciousness; what's good for you...I think everybody has it, if you take something and you feel something is wrong... You have to listen to your body...</i></p> <p><i>1269) That's right you've got to listen to your body...work something out with your doctor.</i></p> <p><i>SH53) With the option for Warfarin... I made the decision at the hospital that night I wasn't having it. I just felt that I didn't need it</i></p> <p><i>577) They put me on Riveroxaban for blood thinning as Warfarin did not do any good. I just wish they could regulate it somehow. Because it is not regulated, it makes you feel miserable.</i></p>
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VI. Some participants stated that they had been pressured into making decisions about taking medications they really did not want. Some felt guilty about not wanting to take the medication and believed they were unable to express or explain their reluctance while others stated they took the medication to keep their physicians happy.

Theme	Exemplar Quotes
<p>Pressured into taking medication</p>	<p><i>720) I am an individual. It's like this, this and this, you have to do this. At the beginning, I already fought not to take the medication until I felt that I was at the point where I needed to take it. I don't know if I did not understand it or what it was, but I did fight it and I felt guilty.</i></p> <p><i>425) There is a huge ego you have to deal with in some cases and a huge amount of dominance. Surgeons are the top of the food chain. Doctors especially in their specialties are quite high as well in the food chain of the medical industry... It's hard to tell them that they don't understand what the problem is.</i></p> <p><i>429) I think a lot of doctors will just...maybe it's the hammer effect where everything is a nail, where their specialty is their thing. You can't second-guess it or there's no option to second-guess it.</i></p> <p><i>712) I felt I was pressured rather than ready for the</i></p>

	<p><i>medications that they were recommending.</i></p> <p><i>733) They did not give me any options. They said you have to go on this</i></p> <p><i>2-666) I don't feel that at any time I was presented with alternatives in treatment...</i></p>
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B) Themes emerging from the data that give insight into how patients make medication decisions

This section of the results is the analysis of the themes emerging from the data that provides deeper insight into patient decision-making about medication. Patient beliefs around medication and their perceived needs at any given time appear to be integral to the decision making process and it should be noted that these interact with each other at any given time over the span of time the patient is living with AF and is living with the increased threat of stroke. This means that decision-making about their AF and stroke prevention drugs is an ongoing, dynamic process for many patients; one reason they would prefer to be in ongoing contact with the AF Clinic.

Elements in decision making:

1. Patient beliefs that form the base for choice.
2. Patient needs at any given time that influence choice
3. Patient perceptions of stroke mitigation

1) Patient Beliefs

The following themes and sub themes outline beliefs that patients held at some stage in their AF experience.

- I. Beliefs about doctor as expert
 - i. Doctor makes drug decisions
 - ii. Patients want voice in drug decisions
- II. Beliefs about taking drugs
- III. Beliefs about non-medical strategies
 - i. Holistic approach
 - ii. Use of trigger recognition
 - iii. Use of coping mechanisms

2) Patient Needs for Decision Making

- I. Collaboration with physicians and AF Clinic
- II. Information from AF Clinic Classes, physicians and reliable web sites
- III. Patients need to perceive they are being heard
- IV. Patients need time to grasp diagnosis and stroke threat
- V. Patients need ongoing connection with AF Clinic

1) Patient Beliefs

I. Physician as Expert

i. Following physician directions

Patients told us that they initially wanted total direction from their physicians. They did not want to have to make choices. They were in a fearful and anxiety ridden state and simply wanted someone to take responsibility for all decision-making. For a few patients, this became the norm. They were happy to have little or no input into medication choices even when asked for their thoughts or opinions. Others stated that, when the initial shock of their diagnoses had settled, they did not have the energy or felt too sick to offer input, especially when their physicians did not invite patient participation in making medication choices.

Theme	Exemplar Quotes
Beliefs about following physician directions	<p>669) <i>For most of us, the first time ...you have no understanding. It's overwhelming. They say 'we're going to do this, we're going to do that, and you say, just get me out of here.</i></p> <p>565) <i>They put me right away on Warfarin (first tested me every week and they put me on a test monthly and then now each 2 weeks).</i></p> <p>575) <i>Dr. ----- decided to give me a pacemaker. I had my first pacemaker two years ago with one lead but it was not doing its job and then decided to do an ablation with 2 leads in. But it has been a little bit of a rocky road.</i></p> <p>249) <i>Not all doctors but some doctors are just like, just take the drug and you will be fine.</i></p> <p>416) <i>But when I hit the low and couldn't climb the steps, I just said, Fine, okay I'll just take them.</i></p> <p>429) <i>I think a lot of doctors will just...maybe it's the hammer effect where everything is a nail, where their specialty is their thing. You can't second-guess it or there's no option to second guess it.</i></p> <p>R2) <i>I am the major stakeholder in the decision-making process. I appreciate when physicians listen to what I say and hear me. They should strive to be on the same page I am on instead of the reverse.</i></p>

ii. Patients begin to want a voice in choosing their medications

As noted above, most patients once the initial shock of an AF diagnosis had worn off, wanted to work more collaboratively with their physicians around medication choices. They had started to become more informed and wanted knowledge from

the AFIB Clinic and their physicians about any options they might have. They believed that they had to right to make choices about any medications that were prescribed.

The patients in our study had mixed experiences around collaboration with their physicians in the AF Clinic. Some believed they were not given options, some believed their unanswered questions denied them options, and some believed that they were pressured with threats of poor outcomes into taking medications. Others had more positive experiences but said they sometimes felt constrained in making choices they perceived their physicians would not like; it seemed to patients that the options were presented in a weighted manner rather than leaving choice totally open.

Theme	Exemplar Quotes
Patients begin to want a voice in choosing their medications	<p>470) <i>Maybe this is an opinion but I think the physician should be providing you the information as a tool to make your decision as opposed to making your decision for you.</i></p> <p>685) <i>It's not that the cardiologist or the doctors do not know, they know if they have tried this on 20 people, but they do not know me, so that's where I have to step in and say something is not right.</i></p> <p>733) <i>They did not give me any options. They said you have to go on this... it is to keep the clot from forming so that if you ever get a stroke, you will be safe. There is no danger of getting any stroke that is what they said.</i></p> <p>2-666) <i>I don't feel that at any time I was presented with alternatives in treatment...</i></p> <p>712) <i>I felt I was pressured rather than ready for the medications that they were recommending...And I thought they were just pushing the drugs for the sake of it. Like I was becoming a lab rat, or something like that.</i></p> <p>2-569) <i>The doctors I went through they always said: Why aren't you on a blood thinner?-Because I don't wanna be. -I kept at it and then after a while I just said OK I'll go on board if it makes you guys happy</i></p> <p>154) <i>Yeah. If you know, Dr.---. when I told him I said that no I not going to do anything when he was giving the options he kind of gave that upwards look "Are you sure?" Kind of thing and back down,</i></p> <p>414) <i>I don't have a back-bone. I'm afraid to say anything (in case they) maybe stop treating me.</i></p> <p>427) <i>It's hard to tell them that they don't understand what the problem is.</i></p>

II. Beliefs about taking drugs

Many patients indicated that they disliked taking drugs. They were unsure of any toxic effects the medications would have on their bodies. These patients tried to avoid taking drugs to treat the AF by pushing for ablation treatment and were less sanguine about taking anti stroke medication, often choosing a less effective drug or none at all.

Theme	Exemplar Quotes
Beliefs about taking drugs	<p>134) <i>I just don't like taking pills. I would rather do things the natural way. I would just rather take supplements, change the way I eat, or if I had to exercise more. Or whatever.</i></p> <p>734) <i>Then someone told me it (Warfarin) is a rat poison.</i></p> <p>123) <i>I still wanted the ablation. I wanted to get off all the drugs.</i></p> <p>3-820). <i>Ultimately I decided to have the procedure (ablation)...I was concerned about all these medications...</i></p> <p>2-57) <i>I don't like taking medicine. If I am forced to take I will take it, but I really don't like it. An aspirin seems an easy medicine to take.</i></p> <p>591) <i>...I have kind of decided that technology improves with time – so I've taken a wait and see (approach).</i></p> <p>1289) <i>That's the whole thing that everybody has to go through individually and come up with the answer that is right for them.</i></p>

III. Patient beliefs about non-medical strategies.

Many patients, especially those who disliked taking medication, believed that there were several strategies they could use to decrease the number of AF incidents and the threat of stroke. They believed taking a holistic approach, recognizing and dealing with AF triggers, and employing coping mechanisms were all beneficial for their ongoing wellness.

Theme	Exemplar Quotes
Patient beliefs about non-medical strategies	<p>250) <i>You've got to look at the whole picture.</i></p> <p>265) <i>It's like trying to separate the noise from the signal. I mean there's going to be a little bit of both in it (emotion and physical)...there needs to be a holistic approach to figure out what is normal and what should happen...I mean if you are in an abusive job or high stress job or have an abusive partner... just fixing a small part of the mechanics doesn't fix the issue.</i></p> <p>752) <i>I would like to see more of the 'other' options available...</i></p>

	<p><i>the medical community is by large is very dismissive of the holistic medication and if you go to them and suggest that I should take this vitamin or this pill, then they just dismiss it.</i></p> <p><i>You need to take this kind of medication (prescribed by physician). I find that to be very discouraging.</i></p> <p><i>42) A couple of years later now it seems to...whether I've helped figure out what triggers it, trying to get better sleep, trying to ensure that I have some regime of exercise, and trying very hard to remain calm, that seems be difficult to manage still.</i></p> <p><i>849) I really wanted to take some time to understand my lifestyle choices and how they impacted...understand what my triggers are, see if I made some lifestyle changes if that would help alleviate some of the symptoms and just try to live a healthier lifestyle to see how that would contribute and it made a big difference</i></p> <p><i>741 I went to India and I went to a Swami's ashram for a week and learnt yoga. And I started doing the breathing exercises regularly, Pranayam, they call it, and that has helped me a lot. My BP is under control and that never happened before.</i></p> <p><i>1140) I do massage and chiropractor...I get lots of sleep and I exercise a lot more than I used to. I see a trainer 5 days a week. That is the only way that I go. I know that it is a benefit.</i></p>
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2) Patient needs for decision making

I. Collaboration with AF Clinic and physician

All of the patients told us that wanted to have discussions with AF clinic staff and their physicians about all of the possibilities and options that were open to them. Discussing and working through all the available alternatives makes everything clearer and allows for a more decisive choice. Patients also noted that they need one than one visit, more than one conversation to be really able to make an informed choice.

Theme	Exemplar Quotes
Collaboration with AF Clinic and physicians	<p><i>302) There is kind of an integration I think that you have to make between the doctor's advice and your own reasoning. For instance if S1 doesn't want to take pills just to mask symptoms that's kind of a dimension that has to be added to the whole decision making process...and not that that should define...you know doctors or medicine, but I think there are</i></p>

	<p><i>times you need to say no, that is not the right answer or no, this is not the right interpretation, you must seek a new interpretation. Maybe that is part of the listening process I'm not sure.</i></p> <p><i>307) Yeah, if they would repeat some of the more important things back, because sometimes the important things get overlooked because you are so upset then and your voice tone changes and you sort of get that out of space look... so if they can repeat it to you then they know what I'm going through and they know what I need.</i></p> <p>312) <i>Writing it down or having a little report or having just something that provides me the ability to look at the entire conversation and then pick out pieces that okay I didn't understand that, yeah I thought I understood this but as he talked I didn't. I realized I didn't understand anything.</i></p> <p><i>354) The collaboration piece should be something that...between doctor and patient is something that should be an extended conversation. When I have a conversation with my doctor, any medical professional... I think of things afterwards. The doctor probably has thoughts in their head as well that don't come out...I will think of things afterwards that are sparked by the conversation itself. Can I tell if those things are important or not? I don't know but it would be nice to have that in the context of the actual decisions that are made.</i></p> <p><i>601) We are making decisions as a team – the AF clinic, the nurses, the cardiologist – we are just talking about where I want to be, what is my choice and what is their choice, and we are working through it that way.</i></p> <p><i>1046) We have to be our own advocate and extract what we need from the medical professionals to feel good...I won't leave the appointment until I get the answers I need. I think that is way more beneficial than googling something...</i></p>
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II Information from the AF Clinic, physicians and reliable web sites.

All of our patients, as soon as they had recovered from the initial distress of the AF diagnosis wanted to have extensive reliable information about AF and their increased risk of stroke. They saw this information being provided by the AF Clinic through education classes, in discussions with nurses and physicians and recommended web sites. The patients in this study believed it was their responsibility to seek information but they were aware that misinformation could be dangerous and looked to the AF Clinic to provide guidance about reliable information.

Theme	Exemplar Quotes
Information from the AF Clinic, physicians and reliable web sites	<p>334) <i>They (class) gave me information on things to eat and things not to eat. They also said with the medications that I'm on like the Pradaxa and that. That if you're going to have a Caesar's salad, and you're going to have a big Caesar's salad you'd better be planning on having that for about 3 or 4 days, because you have to dwindle it down or else it does something to your Vitamin K</i></p> <p>2-704) <i>I did (Go to information session)...It was excellent they explained everything very clearly... but the presentation was good basic general information...for me and for others that have done any research in the past didn't add anything...This is the general, but what is my situation, what am I suppose to do, I am still concerned: Am I at risk of a heart attack, a stroke...</i></p> <p>3-821) <i>The program in Calgary is phenomenal, the AFIB clinic, all of the support you get, the lectures, the study groups...like night and day compared to my experience in BC...I think I had one consult with the doctor in BC...polar opposites really.</i></p> <p>E030) <i>Oh yes. I really thought they were good. (Education sessions useful). You could sort of identify. It was nice to meet people that were in the same boat... You didn't feel like you were alone...this medication...this side effect...</i></p> <p>E061) <i>I have lots of pamphlets (from my doctor). He's (cardiologist) very good when you're in there. You're not rushed or anything. He gives you lots of information.</i></p> <p>663) <i>Some of the options were presented to me. These are the options, these are the choices. Maybe they made an assumption that I really knew what the consequences were and I don't. I go away and I start looking at it.</i></p> <p>521) <i>If I don't have enough knowledge, I will choose not to do anything. I'll stop. Until I absorb this I'm not going to move. I'm not changing anything</i></p> <p>964) <i>I would like a place (website) that is reliable. The doctor can't spend all day with each one of us...</i></p> <p>1114) <i>it's a real slippery slope with the amount of information out there...it's a really tough thing to navigate through...</i></p>

III Patients want to know they are being heard

A major concern for many patients was that they were not sure that their physicians were really listening to their concerns and questions with respect to drug choices. They were afraid they were receiving generic rather than personalized information. It was important for them when making choices that they perceived that the information they were being given fitted who they were and what they wanted.

Themes	Exemplar Quotes
Patients want to know they are being heard	<p><i>300) I don't know what you can do to have the assurance that you're being listened to. It's a difficult...As an analogy, if you have a child who doesn't understand what is going on, the parent makes choices in the child's best interest. That's kind of the same...you want somebody to be there to make decisions in your best interest but also with the context and understanding of who you are and what you've been through and what you want.</i></p> <p><i>428) When they dismiss your description of what is going on it's hard to tell them no, no, stop I know that you're a doctor and I know that you went through 12 years of school but you don't understand what I'm going through yet, let me continue to tell you.</i></p> <p><i>432) I'm afraid to say that (you don't understand), especially to a specialist. You know, they can...you're pushed back and you're pushed back.</i></p> <p><i>275) I tell him but as you said sometimes you just don't know how to say it sometimes. My chest feels like its pumping too hard. Part of the communications gap maybe simply the language and the communication between (a doctor and a patient).</i></p> <p><i>440) I guess it (what I told the doctor) didn't fit what they thought was the issue or at least it didn't make sense. So for whatever reason it was discounted as who knows...maybe on my files say this guy is hyper sensitive, he's got way too much interest in his own health. I don't know.</i></p>

IV Patients need time to grasp the diagnosis before making decisions

As noted in the patient beliefs section, our participants needed to have time to grasp the ramifications of their diagnosis and why their physicians were asking them to make choices about anti stroke medication. They needed time to have better clarity of mind as well as time to gather and assimilate enough knowledge to make an informed choice. They noted that they felt “foggy” after an AF incident.

Theme	Exemplar Quotes
Patients need time to	<i>229) Well yeah...It's an odd place to be in. You're taking in</i>

<p>grasp diagnosis before making decisions</p>	<p><i>information. That at least your first exposure to it is completely foreign to you but has the highest stakes you could ever have for yourself. You're making medical decisions. You are essentially making life and death decisions and it's being told to you in Greek)...it's like somebody from a different country explaining to you about a car crash that you are about to have... if somebody told you that sometime within the next hour you're going to have a car crash and then starting to explain it to you in terms that you don't understand, and that you say just a moment and write this down and I'll go back to Google and research that so I can actually interpret what it is that you are saying.</i></p> <p><i>524) When I met with Dr. ---, he was pretty good and he did give you the time... but sometimes it's almost like you need a second appointment with them just to kind of review after you've digested everything. Can I come see you again?</i></p> <p><i>357) I will think of things afterwards that are sparked by the conversation itself. Can I tell if those things are important or not? I don't know but it would be nice to have that in the context of the actual decisions that are made.</i></p> <p><i>501) I think with information overload you just need time to absorb and need time to actually understand what was said to you.</i></p>
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V Patients need more follow up from the AF Clinic

There was unanimous agreement among our participants that patients were not connected with the AF Clinic for a long enough period of time to take care of all their needs. There was concern that if patients had a blip in their AF, wanted to know about newer anti stroke medications or have ongoing check ups to give them security, there was no way for them to access the Clinic unless they had another referral which they may or may not receive. They often did not perceive that their family physicians could monitor their health adequately.

Theme	Exemplar Quotes
<p>Patients need more follow up from the AF Clinic</p>	<p><i>659) It's not as though you can call the AF clinic and speak to someone.</i></p> <p><i>2-741) We are stuck with meds...What bothers me is that I go to my doctor to extend my prescription, but he is not a cardiologist... I am not checked if I should up them or down them...(GP says) If it's not broken so don't fix it... he just gives me another prescription for another 6 months and I just continue. But I am not checked if the strength..</i></p> <p><i>2-745) That is my point too (no check ups). How do they</i></p>

	<p>know ?...</p> <p>2-760) <i>Should we be seeing somebody specifically on something, should we do some tests that we haven't done? Might identify something before a person has a heart attack, before a person has a stroke...Are they monitoring?</i></p> <p>1231) <i>I've had my family doctor change my dosage on mebecause they are reacting to the symptoms I present at the time and then you get into the specialist at the AF Clinic and then they say oh we need to move you back up....and you shouldn't do that.</i></p> <p>1016) <i>Every time I phone the AF clinic with a change in my condition I find out that I've been discharged from the AF clinic and that I need another referral. This is a yearly thing and I don't understand why I can't be kept on the AF clinic books.</i></p> <p>1181) <i>My point is that I'm troubled by the fact that people are discharged from the program when they shouldn't be and they find out when they call in and then have to go get another referral. When someone has cases that are severe they should always be in the program. It's not like it's going to change overnight.</i></p> <p>1088) <i>I would like to be able to call the AF Clinic and not be discharged this time... when I did call (AF Clinic) I was asked what blood thinner I was on and I said that I was on Aspirin 325 and she said didn't you know that once you reach a certain age aspirin is no longer enough and you should be on this...(different drug) that was a bit of a shock.</i></p>
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3) Patient perceptions of stroke mitigation

I Patient perceptions of the importance of anti- **stroke** medication

There appeared to be little consensus among participants around the importance of anti-stroke medication. Most of the participants appeared to be more concerned with controlling the AF rather than dealing with the heightened risk for stroke. We noted that when we raised the question of the importance of decision-making around anti-coagulant drugs during groups or interviews many people chose not to engage with the topic while others quickly deflected the group in a different direction. In our comment sheet we purposefully asked in the Reflect group for thoughts around living with the increased threat of stroke and how that might affect their choices. Several participants chose not to answer, some were almost fatalistic in their outlook, some concerned, others said they did not ever think about it and one participant noted that he did not believe there was enough emphasis put on the risk for stroke.

Theme	Exemplar Quote
Patient perception of the importance of anti-stroke medication	<p>1079) <i>If you're going to have a stroke you are going to have a stroke.</i></p> <p>R1) <i>You have to learn to live with it (stroke possibility), you can't let it control you. None of us will get out alive</i></p> <p>R2) <i>I don't ever think of having a stroke. I had to be talked into switching from ASA to Warfarin.</i></p> <p>R3) <i>I think about it every time I have an incident.</i></p> <p>R4) <i>Makes me nervous. My cardiologist is keeping me on Apixiban to help reduce the possibility of stroke.</i></p> <p>R5) <i>My single biggest concern and risk. We tend to focus on symptoms of AF and stroke mitigation comes across as a secondary rather than a primary risk.</i></p> <p>1077) <i>I'm relying on the Pradaxa for me...you rely on that blood thinner....there's not much else that you can do. (to prevent stroke)</i></p> <p>2-625) <i>The doctors want to put her in blood thinner-I know blood thinner is a lot of trouble...I didn't want her taking blood thinner. I know that is lot of trouble?</i></p> <p>1063) <i>There are so many side effects, is it worth being on the medications?</i></p> <p>2-601-<i>Since that time (an AF episode) they asked me to take baby aspirins. -I didn't take right away because I didn't think that was serious</i></p> <p>1081) <i>For stroke, I kind of think I'm an average guy. The AF has increased the risk? I don't really know – I just park it</i></p> <p>R8) <i>Stroke is the greatest fear and makes me realize that AF is not a trivial 'disease'</i></p> <p>1083) <i>Stroke is the big risk for all of us in this room. It's not the AF, it's the stroke, a lot of the medications that we're on are for the symptoms of AF so that we'll feel better about it in a lot of cases...that's what they're doing...</i></p> <p>1120) <i>With me it (AF) doesn't affect my life... the only thing is when I take my medication in the morning, my heartbeat goes down to 40 or below...I get lactic acid in my legs and have to sit down and do some paperwork... I'm not concerned about a stroke...</i></p>

II The experience of fear and anxiety emerged as a theme, however, they predominantly recounted being fearful of having another AF incident rather than worry or anxiety about stroke. We heard many more discussions about what patients tried to do to avoid an AF incident, rather than being focused on what they were doing around stroke prevention

Theme	Exemplar Quotes
Fear and Anxiety	<p>613) <i>We are trying to keep all the triggers down, but at the moment I am dealing with the triggers and keeping the medication that will help it as well. Trying to get there is very frustrating.</i></p> <p>214) <i>But that initial (time in ER) where they're talking to you (about cardioversion), there is 6 people around you telling you this could happen, this could happen. It's kind of scary.</i></p> <p>850) <i>If I made some lifestyle changes if that would help alleviate some of the symptoms and just try to live a healthier lifestyle to see how that would contribute and it made a big difference</i></p> <p>246) <i>But thankfully I've had one episode in probably the last two years. But I try to keep it under control. I've got to get my sleep. I've got to eat properly. I take my vitamins.</i></p> <p>1075) <i>You get depressed, you can't do that...I'm afraid of getting into situations where my heart would take off, which was happening to me...where am I going to go for help...?</i></p> <p>245) <i>Look how early I was today...I was here at 9:30, because I don't like to be late, I don't like to be rushed because I know that will trigger (an AF incident).</i></p> <p>580) <i>You sort, what you do is to wait for something to happen (AF)... specially on holidays you hope it doesn't happen when I am on holidays...You always think about that, all the time...</i></p> <p>E015) <i>You're scared to go anywhere because it could happen somewhere where they don't have my records. I had a couple of cases (AF) where I was in the hospital in Penticton and Lethbridge.</i></p> <p>R7) <i>Anxiety is constant. The unknown future is worrisome.</i></p>

III The patients in this study were aware that we were gathering information about their decision making experiences to form a base for the development of an e-tool to be used collaboratively with their physicians. Most said they supported anything that would be helpful, but they still stressed that time to absorb the information was important. They were wary of making decisions without time for personal research and stressed that it took time for them to recover clear thinking after an AF event. Many participants appeared to want any decision making tool to be available on line as well as being used collaboratively within the AF Clinic. They believed it would give them more reliable information to consider.

Theme	Exemplar Quote
Patient Perception of	R8) <i>A computer assisted decision making tool would be one</i>

<p>usefulness of a collaborative decision aid</p>	<p><i>of many ways we use to make decisions</i></p> <p><i>R9) Ultimately I count on my specialist for his input</i></p> <p><i>1104) I would like to see the number needed to treat for the stroke preventative drug, how many people you treat to help one...</i></p> <p><i>1105) I don't want to waste my doctor's time with this stuff. He might not have the answers on his fingertips...What I'm suggesting is that this website, this information source...it needs to be deep.</i></p> <p><i>1104) I would like to see the number needed to treat for the stroke preventative drug, how many people you treat to help one... I don't want to waste my doctor's time with this stuff. He might not have the answers on his fingertips...What I'm suggesting is that this e-tool, this information source...it needs to be deep.</i></p> <p><i>1108) It (e-tool) has to be in layman's language.</i></p> <p><i>1118) I like your vocabulary better. The day you find out you have AF you have to go home and think about it... Talking to people is excellent. That is why I chose this over the one-hour interview. I wouldn't have missed this...</i></p> <p><i>1127) it (e-tool or website) could have a "Dear Abby" component where everybody has their own AF situation, but if they are writing into this place, the webmaster could start to see common questions and he/she could build pages with information about it... If the website once it got wheels, it could be useful and go in so many directions. People living with AF could learn all kind of things about living with the condition.</i></p>
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C) What is most important to participants: an emerging theory

Through every phase of this study we noted that participants appeared to be more interested and concerned about medications, surgical interventions, and non medical strategies that could prevent an AF incident rather than engaging in discussions about stroke prevention medication. The participants were all aware that the focus of the study was decision making with respect to anti-coagulant medications, yet, when the facilitators tried to approach the subject, participants and interviewees would deflect the focus into a default discussion of AF and what they were doing to try to avoid another occurrence. It seemed that avoidance of an AF episode was of primary importance:

"You're scared to go anywhere because it (AF) could happen somewhere where they don't have my records. I had a couple of cases (AF) where I was in the hospital in Penticton and Lethbridge." (E015)

The threat of stroke came into sharper focus immediately after an AF incident only, to once more, appear to lose primary importance as they concentrated on trying to control the incidence of AF episodes.

"I think about it (stroke) every time I have an (AF) incident."(R3).

This opens up a question around patient beliefs with respect to AF and the concomitant increased threat for stroke. It would appear that many patients seem, at some level, to believe that if they control the incidence of AF episodes this somehow translates into lessening the threat of stroke. In the thematic analysis (section B) of patient decision making processes we noted the emphasis participants put on trying to control the number of AF episodes discussing medication versus ablation solutions and their belief in, and strict adherence to non-medical prevention strategies. These strategies included observance and avoidance of dietary, sleep pattern and stress related triggers. Most participants had tracked their emotional and physical status prior to an AF episode and had instigated lifestyle changes, both minor and major, in an effort to avoid an AF incident.

"We (participants) are trying to keep all the triggers down, but at the moment I am dealing with the triggers and keeping the medication that will help it (AF) as well." (613).

Participants appeared to be very involved in sharing such experiences and learning from each other. In contrast, they were much less involved in discussing the threat of stroke and what prevention measures they were taking.

"For stroke, I kind of think I'm an average guy. The AF has increased the risk? I don't really know – I just park it" (1081).

"I don't ever think of having a stroke. I had to be talked into switching from ASA to Warfarin". (R2).

"If you're going to have a stroke you are going to have a stroke". (1089).

Having noted the reluctance to discuss the increased threat of stroke and the use of anti-coagulant drugs during the Set and Collect phases of the study, we tried to initiate a discussion about living with the heightened possibility of stroke by using a poster suggesting there was "an elephant in the room" with respect to the stroke risk. Once more the response was muted and somewhat evasive. In our written comment sheets, four of the nine participants did not respond, only two participants noted that they were concerned and one participant did reflect our impressions about where patient concern was focused.

*"My single biggest concern and risk? We tend to focus on symptoms of AF and **stroke** mitigation comes across as a secondary rather than a primary risk". (R5)*

Despite bringing the risk of stroke to the forefront, once more the themes around controlling atrial fibrillation drew the most interest and discussion, confirming the theory that most participants' primary concern was in controlling the AF.

"I mean that I have found that certain things help and certain things hinder. I will keep on that and I'll keep seeing if I can kind of navigate that path." (157).

"I do think I'm lucky...I manage to control the stress...I just walk away from it. I want to be around for a few more years..." (918).

This leads to conclusion that the majority of patients in this study may choose to "park" the increased threat of stroke. They remain somewhat aware of the threat but are much less involved in avoiding a stroke than they are in attempting to avoid another AF episode.

Discussion

As noted above we found little research that had investigated how patients made decisions about anticoagulant medication. Only the younger very active patients (2) who hiked or mountain climbed in Alberta's back country told us that bleeds were of concern to them in their anticoagulant medication choices. However many participants included the six treatment characteristics outlined in the Moia, Mantovani et al. study (2013). Our study, asking participants to talk about how they made medication choices, allowed for more depth and breadth with respect to their thought processes and the factors they considered when making choice.

The patients in this study had to make treatment decisions about their AF and were also asked by their physicians to make decisions about their anti-stroke medication at the same time. As we noted above, much of their discussion was focused on controlling the AF, which appeared to them to be the major issue. It was unclear if this was patient or physician generated. All of the participants were aware that they had an increased risk for stroke and we were able to generate some discussion with respect to anti-coagulant drugs. The major part of the data that emerged, however, was a more general understanding of the processes patients employed in decision-making to try to control the number of AF incidents they experienced rather than decisions around stroke mitigation.

At a theoretical level the findings pose several questions for physicians working with AF patients. We have found that AF patients are more focused on preventing an atrial fibrillation episode than in stroke prevention. They appear to be more afraid of the possibility of an admission to emergency with an AF incident than in the possibility of stroke. This may be fear of the known as opposed to a somewhat nebulous possibility of stroke, which is outside their experience. It may be a subconscious belief that if they control the AF, they are also lessening the threat of

stroke. In this case, the foundational beliefs we noted around an aversion to taking medications unless absolutely necessary, may in part explain their apparent disinterest in anticoagulant drugs. Participants wanted to believe they had some sense of control, some agency over their diagnosis. It appeared that taking steps to try to avoid atrial fibrillation gave them this sense of control, while stroke prevention medication did not have the immediacy necessary to ignite their interest and participation.

The data suggests that there are three perceived major tasks for patients after an AF diagnosis: 1) They have to decide how they are going to treat the AF, whether by medication, ablation or a combination of both. While not all patients are informed about the possibility of ablation, there are major decisions to be made at a time when they are still absorbing the shock of the diagnosis. 2) Patients start to try to control the AF by identifying triggers, devising coping strategies and making major lifestyle changes. This task appears to develop over time as they research their illness and forms a central part of their focus on prevention. 3) Patients are informed of the increase risk for stroke and are asked to make medication choices about anticoagulants.

Patients are asked to deal with the diagnosis, make important decisions about AF treatment and how they are going to live with the possibility of subsequent AF episodes. It may be asking too much to add anticoagulant choice into the mix in a single appointment. The information about increased vulnerability to **stroke** and asking them to make **stroke** mitigation medication choices may be overwhelming in the face of the primary diagnosis. Stroke mitigation medication is possibly perceived as “parkable” at the time and if not discussed as a separate very important aspect of a patient’s illness when they are less anxious may stay as a secondary concern only brought to mind after an AF incident

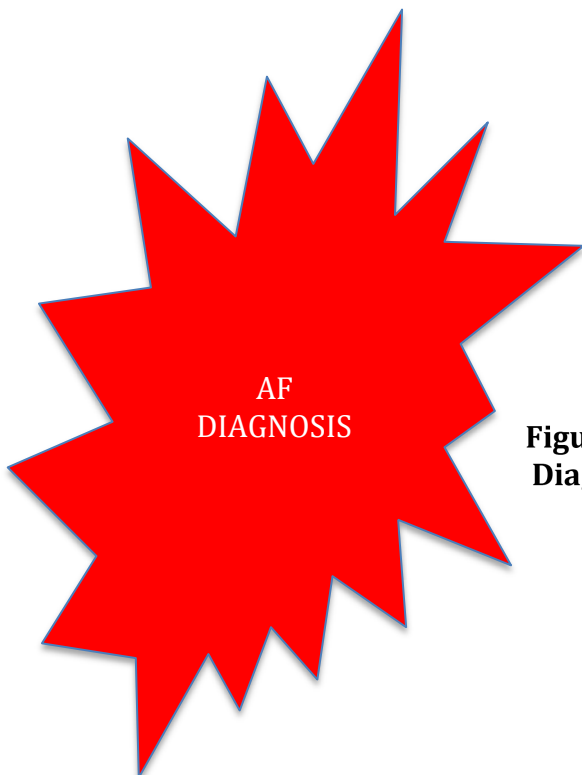
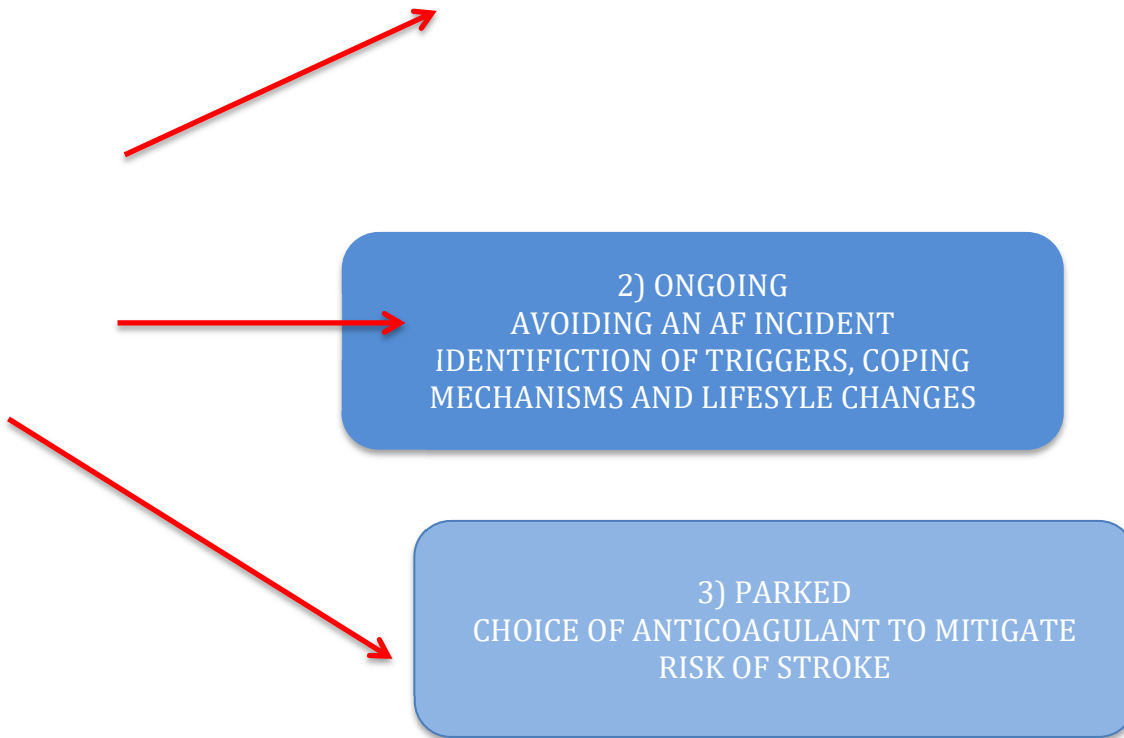


Figure 1. Focus For Patients Post Atrial Fibrillation Diagnosis

1) IMMEDIATE
DEALING WITH AF
CHOICES OF MEDICATION AND/OR ABLATION



We believe that further research about why patients focus on AF control rather than on stroke prevention medication is merited. Patients told us that they believed the atrial fibrillation was unlikely to cause their death, yet they were disengaged in direct stroke prevention, a condition more likely to have catastrophic outcomes.

Strengths and Limitations

This study was conducted through all phases of the research by patients with experience in making difficult medication choices for their various chronic illnesses. Recognition by participants that the researchers shared their experience of having to make somewhat complex medication decisions may have allowed participants to openly share their lived experience at a deeper level than would have been possible with “traditional” health care researchers. There was no perceived power imbalance and both researchers and participants were focused solely on patient concerns and perspectives (Gillard, Simons et al., 2012; Berger, 2015). The direction of the research was driven by the patient participants and they were an integral part of the analysis process (Marlett, Shklarov et al., 2014). We engaged with 31 AF patients, a large sample for a qualitative research project and the data is authentic, thick and rich. Saturation was reached after the second

focus group, but we decided to continue with a third Collect Group and Collect interviews to expand the richness of the data within the identified topics.

Transferability of the findings may be limited as the participants were all from the same large healthcare system (Alberta Health Services) and all had the common experience of attending the Calgary AF Clinic. So there may be differences of experience and service delivery within other systems. With the exception of two patients, our participants were Caucasian. Participants from different cultural, ethnic and socioeconomic groups may have different lived experiences and further research is recommended.

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