

# Patient Perspectives on Stroke Prevention Therapy Decisions in Atrial Fibrillation: A PaCER Qualitative Study

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**Introduction:** This project is part one of three linked projects with the long term objectives of reducing avoidable stroke and bleeding events in patients with non-valvular atrial fibrillation (AF) by ensuring that they choose stroke prevention medication based on complete and unbiased information, and in keeping with their personal preferences.

**Objective:** The first phase outlined here is to explore patient experiences, concerns and preferences for treatment decision-making related to stroke prevention in AF.

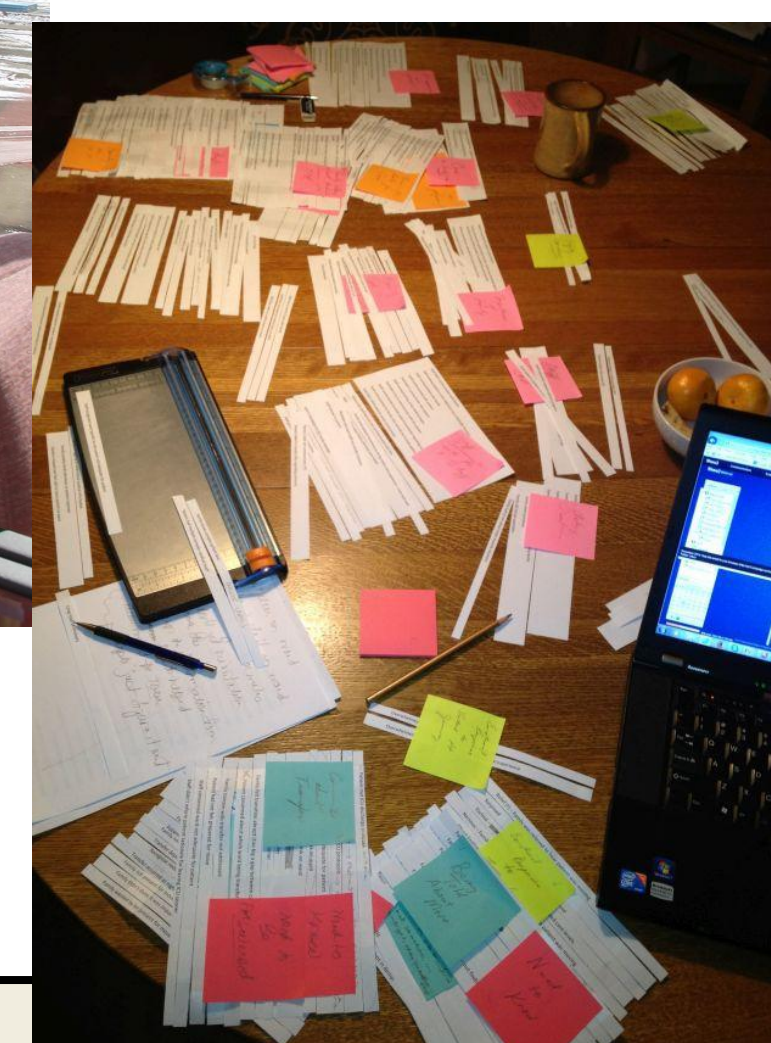
## Method

### Participants

- Purposive sampling
- Screened over 80 patients to gain cultural, age and gender diversity
- Recruited 30 (18 males) participants aged 46 to 82, who had attended the AF Clinic in the last 12 months



In this study, insight into patients decision making processes was gained from discussions about AF incident prevention and stroke mitigation medication.



### Data Collection: PaCER Set / Co-design – Collect – Reflect structure

- A co-design focus group with participants to guide data collection
- Three focus groups (7,7,6 participants respectively) and 7 interviews
- Reflect focus group (9 returning participants) to check on and expand findings.

### Data Analysis

- Participatory grounded theory
- All groups and interviews were audio-taped and transcribed, with process notes taken. Flip charts to ensure ongoing accuracy of data recording.

## Opportunity

- 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 experiences with selecting an antithrombotic medication have not been studied.
- This PaCER qualitative study, the first phase in a three part project to design a shared decision making computer programme assisting physicians and patients to make informed choices about stroke mitigation therapy, clarifies how AF patients make their medication choices.

## Major Findings

- Patients appeared to put more stress on avoiding an AF incident than on choosing a stroke prevention drug. *They appeared to believe that avoiding an AF incident was a factor in avoiding stroke.*
- Despite being aware of their heightened risk of stroke, patient participants appeared to be *more concerned about medication choices, surgical interventions and non medical strategies to prevent an AF incident than stroke mitigation medication.*
- It is possible *that a desire to have a sense of control over their situation leads patients to focus on AF treatment medication and lifestyle changes, while “parking” the more nebulous threat of stroke.*
- Patients appeared to be overwhelmed by the experience of an AF incident and may *focus on prevention of a known episode rather than the possible threat of the unknown (stroke).*

### Elements in decision-making

The data suggest 3 major decisions that AF patients have to make after diagnosis:

- Treatment for atrial fibrillation
  - Possible lifestyle changes
  - Anticoagulant medication
- At any given time patients’ perceived needs, beliefs and experiences interact.
  - Patients’ circumstances change over time.
  - Patients may need to revisit decisions.

## Results: Three Primary Elements in AF Patients’ Medication Decision Making

### PATIENT NEEDS

- Medication fits life style:** *“I choose not to go the Warferin route as I don’t want to bleed in the mountains. Aspirin is the best-worst choice”*
- Tolerance for medication:** *“Lots of GI issues with Pradaxa. Chronic diarrhea was the big one”*
- Affordability:** *“Cost is an issue. I’m on a fixed income Pradaxa is very expensive”*
- Collaboration with physicians:** *“We are making decisions as a team. The AF Clinic, the nurses, the cardiologist – we are talking about where I want to be, what is my choice, what is their choice, and working through it that way”*
- Time to do own research:** *“I’m still frustrated, confused that I’m being offered stuff I don’t know anything about”*
- Time to grasp diagnosis and stroke threat:** *“I felt I was pressured rather than ready for the medications they were recommending”*

### PATIENT BELIEFS

- Following physician directions:** *“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”*
- Beliefs about taking drugs:** *“I just don’t like taking drugs. I would rather do things the natural way...take supplements, change the way I eat, exercise more, whatever”*
- Beliefs about the importance of anti-stroke medication:** *For stroke, I think I’m an average guy. The AF has increased the risk? I don’t really know. I just park it. If you are going to have a stroke you are going to have a stroke”*
- Usefulness of alternative treatment:** *“I really wanted to take some time to understand my lifestyle choices, understand what my triggers are and see if I made some changes if that would alleviate some of the symptoms and it made a big difference”*

### PATIENT EXPERIENCE

- Living with fear of AF incident:** *“You’re scared to go anywhere because it could happen somewhere where they don’t have my records”*
- Living with anxiety:** *“Anxiety is constant. The unknown future is worrisome...I don’t like to be late, I don’t like to be rushed because I know that will trigger an AF incident”*
- Living with depression:** *You get depressed...at the moment I am dealing with the triggers and keeping the medication will help as well. Trying to get there is very frustrating?”*
- Living with uncertainty:** *“I think it’s exceptionally important for physicians to understand the state of mind when we make decisions. It’s very close to the idea of being told that you’re going to be in a car accident in just a few minutes. You don’t how, you don’t know when, you don’t know exactly what’s going to happen. There is a lot of uncertainty”*