

## **Who should choose, you or your doctor?**

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**By Dr. Gordon Guyatt**

**(Spectator headline:** Decision should be shared)

**(Spectator subheadline:** Often, there is no single best choice about treatment)

You awake one morning with an uncomfortable feeling in your chest. Your heart is beating very quickly and irregularly, and periodically you experience a distressing 'thump'. You waste little time in getting to an emergency room.

In the ER, the doctor tells you that you are suffering from "atrial fibrillation". The normal mechanism controlling your heart beat is not working, and as a result your heart rhythm is rapid and chaotic.

Medication will slow your heart down, but your heartbeat abnormality will likely continue. As a result, you must confront a difficult choice.

Because of an increased likelihood of clots forming in the heart, patients with atrial fibrillation face a higher risk of stroke. Fortunately, a drug that impairs the body's clotting mechanism ("a blood thinner"), warfarin, cuts the risk of stroke by two thirds.

Unfortunately, anticoagulation with warfarin increases bleeding risk. The most serious problem is a higher likelihood of major haemorrhage from the stomach.

You face a tradeoff. Take warfarin, decrease your risk of stroke, but increase your bleeding risk. Or choose an alternative such as aspirin with a lower risk of bleeding, but also, a higher risk of stroke.

Who should make this decision? And how?

Many medical decisions involve this sort of tradeoff. A medication decreases the risk of a serious complication in the future, but with downsides of cost, inconvenience, and side effects. Because these

choices involve values, or preferences, the right choice for one patient may well be the wrong choice for another. My values and preferences may be very different from yours.

Take the atrial fibrillation example. One patient may be terrified of the long-term disability that often accompanies a stroke, and not terribly concerned about bleeding risk. Such a patient, whom we can label as "stroke averse", will do almost anything to avoid a stroke. She should almost certainly receive warfarin.

A second patient may be horrified at the thought of vomiting blood, and the possibility of imminent death, and less concerned about stroke. Patients like this, who are "bleeding averse", may well be better off if they receive aspirin rather than warfarin.

Traditionally, doctors would make crucial medical decisions, such as whether or not a patient with atrial fibrillation should receive warfarin. These decisions would be wise ones as long as they reflected the values and preferences of the patients.

A cardiologist now working at McMaster, Dr. PJ Devereaux, has studied how patients and doctors respond to the choices that face patients with atrial fibrillation. Devereaux's research showed two key findings.

First, patients were much more stroke averse, while doctors were much more bleeding averse. All else being equal, patients were more inclined to choose warfarin, physicians to withhold anticoagulation.

Second, patients had different preferences. While most patients were extremely stroke averse, a minority were more concerned about avoiding bleeding.

Devereaux found the same variability among doctors. While the physicians were, on average, more bleeding averse than the patients, some doctors proved extremely stroke averse.

So, what does this mean about who should be making difficult medical decisions, and how should they be made?

Devereaux's results suggest that if we leave it to the doctor, fewer

patients will be receiving warfarin than patient values would dictate. Indeed, other research studies have found that many patients with atrial fibrillation who should probably be receiving warfarin are not.

Furthermore, because doctors' values and preferences vary as much as those of patients, whether or not you receive treatment will depend on your doctor's particular preferences.

For many people, this is a frightening situation. The obvious solution is for patients to share in the decision-making process with their doctors.

While the doctor carries the medical expertise, patients are experts in how the illness effects their lives, and in their values and preferences. The best decision requires both types of expertise.

Some patients, however, express reluctance to get involved. They may even resent a physicians' encouraging their participation. Many physicians have heard their patient exclaim, "You are the doctor" in response to unwanted efforts to have the patient assume some of the responsibility for treatment choice.

Devereaux, however, doubts that patient reluctance to participate in decision-making is a big problem.

"Perhaps patients are hesitant because they haven't experienced true, informed decision-making. No one has explained the options in a way they can understand."

Devereaux reports that patients who participated in his study of decision-making in atrial fibrillation were all enthusiastic about applying a similar informed approach to other medical decisions.

So, what is the bottom line for the patient? First, understand that, often, there is no single best decision about medical treatment. Frequently, there are serious trade-offs between benefits and risks.

If you leave the decision up to your physician, the values and preferences driving the choice are likely to be the doctors'. And those values and preferences may be quite different from your own.

So, I would suggest you share in the process of making important medical decisions in your life.

But that's just my advice. The choice, as it should be, is with you.