Patient Perspectives

Stuck in the Middle: Afib Patients on Rate Control

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Those with atrial fibrillation know the symptoms of a wildly beating heart, the fatigue and downright helplessness when trying to contend with the condition. Patients are desperate to relieve those symptoms and will follow recommendations, often without question. For some physicians, especially the primary care providers who aren't as well versed in the details of afib treatments, it appears that rate control is the treatment of choice for everyone — regardless of whether or not they are symptomatic.

Through StopAfib.org forums and events, I hear from thousands of patients, many of whom have shared their experiences about rate control. Many feel so miserable that they can't do anything. To them, it seems like they don't have a life anymore. Afib alone isn't causing this diminished quality of life — it may be the rate control treatment. There ought to be a better solution. Perhaps it's time to rethink the typical treatment of afib patients.

Right now, the atrial fibrillation guidelines recommend rate control for those without symptoms or with minimal symptoms. The ACC/AHA/ESC 2006 Guidelines for the Management of Patients With Atrial Fibrillation state that, "…rate control is a reasonable strategy *in elderly patients* with minimal symptoms related to AF."[1] The European Society of Cardiology's 2010 Guidelines for the Management of Atrial Fibrillation and the Canadian Cardiovascular Society Atrial Fibrillation Guidelines 2010 provide similar recommendations. Yet, many primary care providers put patients on (and leave them on) rate control despite being symptomatic, and not always elderly. Rate control medications simply slow down the heartbeat, while often leaving the patient in afib. So while treating such patients with rate control may not put them at risk today, these patients may suffer the effects years later.

Figure 1: StopAfib.org is a comprehensive gateway to atrial fibrillation information, including information about rate control and treatment alternatives.

When a doctor puts a patient on rate control, the intentions may be justified by the treatment guidelines, but the core, underlying problem of afib is not addressed. By prescribing rate control medications, doctors seek to slow the heartbeat and ease the symptoms, yet symptoms may not let up. However, patients often don't realize why they are taking the medication and may not understand that the drugs won't stop the afib. In addition, many studies have found that patients don't understand the seriousness of afib, and the sit-back-and-wait philosophy of rate control enforces that belief. Doctors may not explain the seriousness of afib (such as the potential for stroke and heart failure), or may not explain in a way patients can understand. Some patients may not even comprehend rate control because of the brain fog and short-term memory loss that patients experience on many rate control medications.

This is where the skill and knowledge of specialists can improve the lives of those with afib. With up-to-date information about the most current treatment options, specialists can provide alternatives. Otherwise, patients, some of whom are feeling the life-altering symptoms of afib, remain on rate control and can be left waiting.

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CONSEQUENCES OF STATUS QUO

Allowing the afib to continue could have some serious repercussions that researchers continue to piece together. The irregular heartbeats can cause remodeling and fibrosis of the heart, and new research has correlated this afib-related fibrosis with stroke.[2] Even on rate control medications, afib patients may have an elevated risk of stroke because rate control allows the haywire circuitry of the heart to continue causing damage. In addition, a recent study published in the *Journal of the American College of Cardiology* found that rate control treatment didn't appear to improve quality of life for afib patients.[3]

In an accompanying editorial, Dr. Paul Dorian, a leading afib quality-of-life researcher at the University of Toronto, wrote that atrial fibrillation treatment strategy, whether rate or rhythm control, has little impact on quality of life, and that symptoms are the most important determinant of quality of life.

He also stated that patients have to accurately convey how the illness affects their daily lives and health in order for healthcare providers to understand the impact of afib, but this can be difficult. Based on the experiences of the patient community, this task is made more difficult when patients and

doctors can't communicate effectively. This disconnect seems to be especially prevalent among female patients, who may communicate more with feelings and emotions rather than with tangible symptoms.

Dr. Dorian also observed that studies suggest that when beta-blocker therapy is used for strict rate control, the potential benefits may be offset by adverse effects, such as fatigue, especially when higher or more frequent doses are needed to sustain those benefits. In addition, he pointed out that studies consistently show that women have a poorer quality of life while in afib, as do those who suffer from depression or anxiety, and that older patients are often less symptomatic than younger ones.

The editorial also stated that while using objective measures of cardiac function to judge quality of life in afib patients seems reasonable, "it is insufficient to merely examine the electrocardiogram of patients in AF to assess the impact of their illness on their well-being. Clinicians need to be aware that patient personality, treatment expectations, and factors unrelated to the arrhythmia itself will have important, potentially determining influences on the extent to which AF causes suffering."[4] Dorian concludes the editorial with some time-tested wisdom: "In an era of increasingly sophisticated and complex technologies used to investigate and treat atrial fibrillation, it is worth heeding the advice of Hippocrates: 'It is far more important to know what person the disease has than what disease the person has.'"[4]

The key for healthcare professionals is in knowing whether rate control medications diminish a patient's ability to enjoy normal activities and exercise. Often, doctors don't realize the impact rate control medications have on patients. Doctors usually see these medications as benign, but patients often have a different view. The energy-sapping, brain-fogging experience of these drugs decreases the quality of life as much as afib itself. They are definitely not benign. As someone who has been on these medications, I personally felt like I was a zombie — and if my brain didn't work, I might as well be dead. After hearing from thousands of afib patients through the StopAfib.org forums and other communications, I have found that too many other afib patients have had that same experience.

That kind of 'zombie' feeling is all too real for many others, too, but it can be worse. Rate control medications such as beta blockers could potentially contribute to dementia or Alzheimer's in afib patients, and could even lead researchers to believe afib patients have those conditions when they don't. Indeed, researchers have found that afib and Alzheimer's are related. However, could the beta blockers that afib patients are taking, which not only decrease the amount of oxygen received by the brain but also cause foggy headedness, lead to dementia or mimic it? Are researchers being led to believe that more afib patients have Alzheimer's than actually do? It's a question worth asking: Is it really Alzheimer's, or could the brain fog of afib patients be from beta blockers?

For the elderly, rate control medications may have an even worse effect, making some patients feel exhausted and unable to even walk up stairs or pick up their grandchildren. Patients may not realize that rate control medications may cause this fatigue, and these medications make it difficult for patients to exercise, too. Coupled with aging, the "watch and wait" approach can lead to a downward spiral of inactivity and diminished quality of life — while nothing is being done to fix the original arrhythmia. At that point, the risk of stroke is possible, so patient health and quality of life potentially gets worse.

A VITAL RESOURCE: SPECIALISTS

Shouldn't afib patients have a chance to live normal, healthy, active lives? Healthcare providers can educate patients about rate control, leading to more informed decisions. Also, having patients treated by specialists is an important way to get them the care that they need. General practitioners may not realize that there are options that can give patients a better life and possibly head off strokes at the same time. Specialists can help their general practitioner peers understand that leaving patients stuck in the middle on rate control may be doing a disservice to patients and their families. One way to raise awareness of the rate control issue would be to share this article with your general practitioner colleagues.

Think of it another way: Would you or your peers choose this treatment option for yourself or for a family member?

Figure 2 (above): The "Can Atrial Fibrillation Be Cured?" section of StopAfib.org helps patients evaluate treatment options through in-depth, yet easy-to-understand, information about procedures such as catheter ablation and mini maze.

Figure 3 (below): To help patients learn more about afib, point them to StopAfib.org, where they can tap into a wealth of information, including videos such as Take a Stand Against Fibrillation and Stroke, which details statistics and the risks associated with afib.

For many, the solution is consulting with a specialist who can tailor treatments to patients' specific needs. Often, such treatments can keep the patient in normal sinus rhythm, and thus, possibly prevent strokes.

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If patients are to be left on rate control and in afib, healthcare professionals may want to be more aggressive in prescribing anticoagulants and helping patients understand the need for very strict adherence to their medication schedules. For example, if there is any question as to whether the patient needs anticoagulants while on rate control, then perhaps we should err on the side of prescribing them, especially for women. In general, patients tend to fear strokes more than bleeds.[5]

Prompt treatment also matters. Patients who have procedures within the first two or three years of diagnosis have the best chance of being "cured" or at least of having their afib markedly diminished. So, instead of taking a "watch and wait" approach, think "the sooner, the better."

Yes, rate control is a recommended strategy in all of the guidelines. But the next time a patient steps into your examination room, take into account the potential long-term risks of rate control and the quality-of-life impact that treatment strategy may have on the patient. Specifically, consider the following as you treat afib patients:

1. **Reconsider leaving patients in afib and on rate control.** Many do not feel better and actually feel worse because of the impact of the medication. However, they may not realize it or know how to convey that to healthcare professionals. So ask them if they feel better or worse after being on the medication. We know that slowing the heart doesn't necessarily improve quality of life, so maybe lighten the dose. For patients who are paroxysmal, going in and out of afib frequently, rate control just may leave the heart rate too slow when they are not in afib, making them feel miserable.

2. **Consider whether patients should try for normal sinus rhythm.** Just because patients don't feel afib, doesn't mean it doesn't impact them. Ask. If they have been on rate control for a while, they may not even realize what it means to feel normal. Maybe such patients could try a short course of rhythm control, and be cardioverted if necessary, so they can see what it feels like to be in normal rhythm again. Since we know that about half of afib patients have sleep apnea,[6] and that there is a high rate of cardioversion failures among those with untreated sleep apnea,[7] probe for the potential of sleep apnea, and do something about it. Could treating sleep apnea or using rhythm control medication keep them in normal sinus rhythm?

3. **Thoroughly evaluate AV node ablation recommendations.** Think long and hard before relegating someone to AV node ablation — especially someone under the age of 80 — because staying in afib all the time can be a miserable existence. Because afib begets afib, remodeling can lead to stroke, and strokes happen even on anticoagulants, AV node ablation could increase the risk of stroke. In addition, the younger patients are when they get an AV node ablation, the longer fibrosis can build up, potentially increasing stroke risk.

4. **Seriously rethink using rate control or AV node ablation in women.** We know that women are much more vulnerable to strokes, and about 60 percent of stroke deaths occur in women. Yet, it appears through the experience of the patient community that more women than men may get rate control. A recent small study in private practice showed that more women than men were referred for AV node ablation, whereas more men than women were referred for catheter ablation.[8] This is true despite the fact that women on anticoagulants spend more time outside of therapeutic range and below therapeutic range than men.[9] Therefore, are we setting these women up for strokes?

5. **Review a variety of treatment options with patients.** With alternatives available such as rhythm control medications and catheter ablation and surgical (maze and mini maze) procedures, afib can be cured or greatly diminished. We have seen more and more evidence that turning to these treatments can give patients their lives back. A study published in the January 2012 issue of the journal *Heart* showed that after a catheter ablation, "rates of stroke and death were no different from those of the general population."[10] That could be the case with surgery as well. So, for afib patients and healthcare providers, a more aggressive approach could be in order. Watching and waiting is just that. Please don't leave afib patients stuck in the middle, between physicians prescribing rate control and the potential for strokes. ■

Figure 4: In the StopAfib.org forums, patients can connect to share information and provide support to each other.

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