Patient Perspective: Digital tools give afib patients more control

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The rapidly emerging field of digital health has truly shown its value during the global pandemic. And with the advent of digital health, we appear to be on the verge of a new era, where atrial fibrillation (afib) patients can proactively manage their care. Innovations in digital health technologies can help diagnose and support treatments for patients with this condition that sometimes eludes detection during in-office visits.

Afib is a complex condition that varies with each individual, and the ongoing digital medical revolution may hold many answers for afib patients.

Today, afib patients use consumer digital tools to assess the frequency of arrhythmias, monitor the effectiveness of medications, and share monitoring results with healthcare professionals.

But how often and to what extent are afib patients utilizing consumer digital monitoring tools? To find out, patient advocacy organization StopAfib.org conducted an online survey from March 30 to April 5, 2021. Links to the survey were included in StopAfib.org newsletters, posted on the organization’s Facebook page and Twitter feed, and shared in a discussion thread on the Atrial Fibrillation Support Forum on Facebook. The survey covered treatment during the COVID-19 pandemic, digital tools, and webinar topics, and received responses from 763 afib patients. The responses revealed much about patients’ experiences with digital tools and their perceptions of healthcare professionals’ attitudes about them.

Afib patients use several kinds of consumer digital tools

In one revealing survey question, 71% of respondents said they are using consumer digital devices to monitor or manage their heart rate or rhythm. The most common digital heart rate or rhythm monitoring tools included KardiaMobile (48%); Apple or another watch (45%); photoplethysmography phone apps (20%); Fitbit (18%); and other devices and apps (12%). Among others mentioned multiple times were the Samsung watch, Garmin, Whoop, and the Cardiogram app. In addition, many respondents mentioned using multiple devices and apps in their daily lives.

The variety of devices and apps shows that those with afib have digital tool savvy and seek a variety of ways to monitor their condition. However, when evaluating this survey information, it’s important to note that StopAfib.org frequently covers this topic, so its Facebook followers and e-mail subscribers are more likely to be digital tool savvy than typical afib patients. Such willingness to embrace digital technology offers an opportunity for healthcare professionals and patients to team up to share more information.

Interestingly, about 2 dozen respondents mentioned medical-grade devices (such as insertable cardiac monitors and pacemakers) when asked about consumer digital devices. This, perhaps, demonstrates a lack of patient knowledge about the differences between consumer devices and medical-grade devices. This finding presents an opportunity for healthcare professionals to clarify the differences. Also, a few patients mentioned copycat devices that are not FDA cleared. Such devices may not be accurate and might lead to ill-advised decisions about medication or treatment. Because patients turn to these devices to feel in control of their afib, healthcare professionals may want to ask patients which consumer devices they are using. According to the survey, some patients reported that their healthcare professionals considered consumer devices to be sufficient for frequent monitoring and did not see the need to order a prescription monitoring device for them.

Afib patients cite a variety of advantages to digital monitoring

For patients, afib can be vexing and frustrating. Paroxysmal patients never know when the afib beast will strike, nor what routine or daily activity they will have to cancel because of it. And those who are asymptomatic may not even know they are in afib.

Respondents reported that digital monitoring tools provide several advantages. For many, the devices offer tremendous mental comfort because afib can be so unpredictable that patients don’t feel like they’re in control of
their bodies or lives. In addition to peace of mind, convenience and ease of use were most often cited as reasons for choosing a device. One of the most vital benefits was being able to determine when afib was significant enough to go to the hospital. Many also explained that monitors allowed them and their healthcare professionals to determine the effectiveness of medications and whether adjustments were needed.

Some respondents also noted that using these digital tools allowed them to exercise with more confidence by providing assurance that their heart rates didn’t rise too high. Some valued the benefits of their devices being able to detect afib during sleep.

Many e-mailed their concerning rhythm strips to their healthcare professionals or uploaded that information through patient portals, and some even took detailed spreadsheets of their afib burden to clinician visits. By doing so, these afib patients felt more in control and knew when to consider having an ablation. And after an ablation, digital monitoring tools allowed patients to see whether they were in afib.

**Few downsides to digital monitoring of afib**

Patients felt that the downsides of digital monitoring are few, with 47% reporting no disadvantages.

Some survey respondents reported that afib monitoring devices didn’t always agree with the assessment by their healthcare professionals, such as a device reporting that they were in afib when their clinician said they weren’t. Accuracy is a concern to them, so patients should have FDA-cleared devices and know how to properly use them.

For seniors who are not tech savvy, devices were sometimes complicated or difficult to use. Another steep hurdle was the cost of devices and monitoring subscriptions, which can exclude some socioeconomic strata of the afib community. Only 1% reported that these costs were defrayed by insurance; others received free, reduced-cost, or loaner devices as part of a study; but 91% paid for their own devices or received them as gifts from loved ones.

For those who are paroxysmal, these tools are valuable. The survey surprisingly showed that 27% of those reporting using digital tools for monitoring heart rate or rhythm are in persistent, longstanding persistent, or permanent afib and thus may find little value in these tools.

Among the disadvantages, disappointingly, some afib patients mentioned that their clinicians weren’t interested in their monitoring results. There could have been many reasons for that. Perhaps for persistent or longstanding persistent patients, their healthcare professionals didn’t communicate that the data might not change treatment since they were in afib all the time. For paroxysmal patients, clinicians maybe didn’t understand the value of helping the patient be proactive in their care or were concerned about the volume of data or lack of a secure way to receive and integrate it into normal office workflows. To avoid the level of disappointment reflected in some responses, it could be helpful to clarify this for patients.

In response to the disadvantages question, some respondents shared their feature wish lists, including constant monitoring and real-time alerts.

**Digital devices + Patients + Healthcare professionals = Empowered care**

With consumer digital monitoring devices, there is tremendous potential for patients to gain more control of their lives and improve their quality of life. Also, with data from these consumer devices, there may be the potential for clinicians to gain more insights into their patients’ afib. As we come out of the pandemic, we’ve seen how digital tools have been valuable in telehealth visits, so we know that leveraging insights provided by these devices may increase the potential for empowering patients to improve management of their afib.

Based on this in-depth survey of afib patients, here are 4 strategies those who care for afib patients could consider:

1. **Have conversations with afib patients about consumer digital devices.** Discuss with afib patients when it would be appropriate to use consumer monitoring devices and how often to send in rhythm strips. In this conversation, healthcare professionals can advise about what kind of device could be most useful for that specific patient and manage expectations about what data to send.

2. **Embrace patient–healthcare professional partnership opportunities.** One survey commenter liked a consumer monitoring device so much that the patient gave one to the doctor. Patients may see things before clinicians, often hearing about them from other patients. Being receptive to new ideas from afib patients may help healthcare professionals treat other afib patients as well.

3. **Discuss using medication reminder apps.** Of those who participated in the survey, surprisingly only 19% said that they are using any form of medication reminder or tracking app, with most simply setting reminders on a phone, watch, Fitbit, or Alexa; others used medication reminder apps, such as Medisafe, Mango Health, or KardiaMobile. For afib patients who are taking direct oral anticoagulants, medication reminder apps could be crucial for taking their medication consistently at the right time.

4. **Encourage participation in research studies and share study findings.** The survey asked patients if they had participated in any research studies that used digital devices. Only 10% of respondents had participated in any such study. The most frequently mentioned study was the Heartline Study, with just 5% of those
using digital devices participating. However, several respondents expressed interest in participating in studies but weren’t sure how to become involved. Others who had been part of aFib studies that involved a digital tool couldn’t remember the name of the study or what the study sought to research. There’s an opportunity to help patients find studies and to share study results with them.

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