

PATIENT VIEWPOINT

From Cardiologist to Patient...

Craig Alguire, MD

I had a partial seizure while riding my bicycle on a trainer one morning. It was 6:10 AM.

Like an aortic dissection, the time and place of a seizure is easy to remember to the minute. At the time, I was not sure what happened and surprisingly not scared. I felt the need to talk, but could not spit out any words. My wife was exercising at a local gym, and I was by myself in the basement. And before I could get too worried, I was completely fine. Just like that. I didn't know what happened so I got on the treadmill, ran a mile, and figured all things were a go. I went off to work and, in an offhand remark, told my wife of the incident.

With my last patient of the day, however, it happened again. This time there was no denying something was wrong. Although I couldn't speak, I was able to write so I scribbled to my patient that I could not talk on the back of an EKG. He promptly got my nurse practitioner and my partner. They gave me an aspirin because, well, we are cardiologists. The working diagnosis was a transient ischemic attack, and they performed an EKG right away. (Again, you use the tools available to you.) My symptoms resolved shortly but this time I was going to the hospital.

In the emergency department, I was a celebrity. Several cardiologists and nurses were waiting for me as soon as I arrived. In fact, I had an immediate cardiology consult from one of the interventionalists. If this were a STEMI. I was going to have a door to balloon time of 10 minutes. But instead my first test turned out to be a noncontrast head computed tomography. This ruled out hemorrhagic stroke, but ruled in a brain mass. I was now missing that diagnosis of transient ischemic attack, if only they could just close that patent foramen ovale (or maybe not)?

"I don't know how to tell you this," my colleague Ryan Madder told me that day in the emergency department, "but you have a brain mass." And just like that, a cardiologist became a patient. My schedule got wiped clean. My call nights were erased. My rounding eradicated. Being a glioblastoma patient was full-time work.

"Glioblastoma multiforme is an incurable disease." Most published reports of treatments for glioblastoma start with a variant of this sentence. Right after I was diagnosed with the disease, I did a quick search on UpToDate and tried to read up on it. Not good news. Limited therapy. A lifespan cut way too short. Survival reported in months, not years. The only "tried and true" therapy was maximal surgical resection and radiation that left an average length of survival around 13 months or so. (Doesn't that technically count as years? I'm grabbing, I know.)

I was diagnosed on October 29, 2015, a day that will live in infamy—at least for me. Brain cancer is graded by histology (not whether it has spread to new locations), and my glioblastoma was a grade 4. This is the worst type of brain cancer. That's about all I knew about it at the time—not something I covered in detail on the cardiology boards or in my routine practice. But all doctors know glioblastoma to be a disease to be feared with a usual course characterized by unrelenting, local spread.

The articles published in Viewpoints reflect the opinions of the authors and do not reflect the policy or position of the American Heart Association, and the American Heart Association provides no warranty as to their accuracy or reliability.

Key Words: cardiologists
■ glioblastoma

© 2018 American Heart Association, Inc.

<http://circoutcomes.ahajournals.org>

From the day of my initial diagnosis, a whirlwind of activity started. A magnetic resonance imaging was ordered, and then a neurosurgeon was consulted. I was admitted, but then discharged in about 2 hours. They did not even consult the doctor if the doctor should be admitted! An admission just seemed self-evident to the emergency department crew.

My sister, an oncologist, started looking into various clinical trials in which I might be eligible to participate. She knew the prognosis for her little brother. When we went to our first appointment with a neurosurgeon at the University of Michigan, I had to give the name of my primary care provider. Like many doctors, I practiced expertly in self-care. I had checked my cholesterol annually and would check my blood pressure every few months or so at the office. I got my flu shots at work. Bottom-line: I didn't have a primary care provider.

My dad, an internist in Grand Haven, Michigan, who was still working at 72, was standing beside me. "Are you still accepting new patients?" I asked. Fortunately, he made room for me in his busy schedule. My family took a strong interest in my care.

I underwent maximal surgical resection of the glioblastoma on November 5, 2015. (This was delayed a few days due to taking that aspirin on the initial day of diagnosis; still wishing for that transient ischemic attack.) The surgery went well and afterward my care team and I looked into various clinical trials. We found a phase 1 clinical trial at Northwestern University in Chicago run by Dr Priya Kumthekar that seemed a good fit.

"I'm Priya," said Dr Kumthekar when we met.

"I'm Craig," said Dr Alguire.

And that's how we left it. Informal. We now hug on the way into the office and on the way out. I never hugged a patient prior to my diagnosis. Now, I do it all the time with my old patients. This is one big way that I've changed.

At that visit with Priya, I signed up for a clinical trial with pembrolizumab, a novel immunotherapy. I was told, however, on the way home that my liver function tests (LFTs) were too high to be included in the trial and it only had 1 more spot. My LFTs could only be 3× the upper limit of normal but mine were 5 to 6× the upper limit. At the time, my only medication was Keppra—a drug that could definitely increase LFTs. We stopped the Keppra and checked labs daily. We also found out that the highest "upper limit of normal" was at North Ottawa Community Hospital, where my dad worked. Fortunately, this was right before Thanksgiving, so the final spot in the trial would probably not be taken that week. We even checked my LFTs on Black Friday, the day after Thanksgiving, and avoided the shopping lines.

This is the benefit of being sick as a doctor in a family of doctors. My LFTs dropped into the required range needed by Monday after Thanksgiving, and we called Northwestern and I was officially enrolled. Even though

this was a clinical trial of an investigational treatment, it is amazing how much of a victory just successfully enrolling seemed.

Every 3 weeks for 2 years I was infused with pembrolizumab. The drug works by blocking PD-L1. This is a marker on many tumor cells that allows the cancer to hide from the immune system. That's about all I know to be honest. I still prefer reading about cardiology, not oncology. Actually, that's not entirely correct. I now prefer reading all sorts of stuff outside of medicine, and when I do read about medicine, I like to get straight to the point. Life is too short.

PCSK9 inhibitors dramatically lower cholesterol and have some marginal benefit? Got it. Entresto is superior to angiotensin-converting enzyme inhibitor for a reduced ejection fraction? OK. Both are expensive and maybe not cost-effective. Makes sense. Of course, I understand the need for researchers to carefully comb through the literature but I'm happy to leave those nuanced debates for others.

Yet, I do love reading. I've now read more nonmedical books in the last two and a half years than in the prior 20 years of my life combined. This includes some books about death like *When Breath Becomes Air* by Paul Kalanithi and Atul Gawande's *Being Mortal*. (Fantastic and fantastic.) But realizing I was going to live a little longer, I went out of the impending death genre to some old standbys: science fiction and books on plant-based diets (I'm still a vegan!). I mix these with a small diet of Richard Russo, Sherman Alexie, and Malcolm Gladwell among others. I now frequently ask people "what is your favorite book?", and then gobble it up. This is definitely another way I've changed.

Halfway through the clinical trial, Priya told me that emerging studies were showing no benefit of pembrolizumab on glioblastoma in general. Yet she followed that quickly by pointing out for people with a high burden of mutations like me, there could be a potential benefit. (Yes, the dreaded, hypothesis-generating, "subgroup" analysis.) To be honest, I didn't review the literature myself and took her word for it. I really hate reading that stuff. I just trusted Priya, and she was keeping hope alive for me. Let's keep infusing this pembrolizumab.

Although being a glioblastoma patient was admittedly full-time work, it wasn't that satisfying. Knowing I needed to have greater day-to-day purpose in my life, I went back to work in January 2016. I was a cardiologist, of course, and not just a patient. I needed to feel that again. I started at a few half days a week and settled in at 3 days a week. No call and no weekends: the "perfect" doctor's schedule.

I have tried to get back to some level of normal with the rest of my life as well. Right now, I have minimal symptoms and actually feel good most days. I continue to exercise regularly and recently ran the Riverbank 25K

Race—a bit off my historic pace but at a respectable sub-7:30 per mile! I also fill my days with swim practices, soccer games, trampoline jumps, and as much fun as I can have with family and friends. This is one way that I have tried not to change.

Yet I think about my diagnosis daily. No, hourly. I am scared.

As a doctor, I know this disease will shorten my life greatly. As I walk through the ICU these days, I understand a little bit more what families are going through as they face daunting diseases: the terror of the diagnosis; the uncertain course of so many conditions we treat; and a great longing for a previous way of life. The uncertainty of what will happen can be horrible. Once you get a plan, half the worry is gone. But getting a plan in medicine isn't always easy.

I also think about my family a lot. I know they have it worse than I do. "You get cut, they bleed," my sister, the oncologist, says about my parents. I get that because I'm a middle-aged father myself with 4 small kids. I listen to songs about losing loved ones, and I get choked up. I listen to happier songs, and I get choked up. I think about the reality of having to leave my kids and wife early in this life, and I cannot face my own mortality. I feel so normal right now, so how can any-

thing be terribly wrong? I think about my wife remarrying, and I try to be a little better husband. I'm trying hard to be a tough comparison.

Of course, this process has given me a new perspective on life. Time is very precious. I wake up each day and appreciate all the things I have a lot more. I appreciate my health at this moment. I appreciate my work as a cardiologist and the strong purpose it gives me to care for my patients. I appreciate my neurooncologist, Priya, and there is really no one else I would rather get bad news from than her. I appreciate my parents and sisters. I appreciate my kids and my wife.

So I am remain grateful for every day that I am still alive, but greedy because I want more.

ARTICLE INFORMATION

Correspondence

Craig Alguire, MD, Spectrum Health Cardiovascular Services, 2900 Bradford St NE, Grand Rapids, MI 49525. E-mail craig.alguire@spectrumhealth.org

Affiliation

Spectrum Health Cardiovascular Services, Grand Rapids, MI

Disclosures

None.

From Cardiologist to Patient...
Craig Alguire

Circ Cardiovasc Qual Outcomes. 2018;11:

doi: 10.1161/CIRCOUTCOMES.118.004991

Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272
Greenville Avenue, Dallas, TX 75231

Copyright © 2018 American Heart Association, Inc. All rights reserved.

Print ISSN: 1941-7705. Online ISSN: 1941-7713

The online version of this article, along with updated information and services, is located on the
World Wide Web at:

<http://circoutcomes.ahajournals.org/content/11/7/e004991>

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in *Circulation: Cardiovascular Quality and Outcomes* can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the [Permissions and Rights Question and Answer](#) document.

Reprints: Information about reprints can be found online at:
<http://www.lww.com/reprints>

Subscriptions: Information about subscribing to *Circulation: Cardiovascular Quality and Outcomes* is online at:
<http://circoutcomes.ahajournals.org//subscriptions/>