Waiting to Start Treatment

You can’t rush into cancer treatment without all the data and options, but waiting to start entails daily distress.

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Manufactured Urgency

Let me make it clear: I don’t think we should be starting treatment right now.

The manufactured urgency to rush into treatment before we know all the information is pervasive and affects patients and physicians. Hell, this post is the sign that it’s affecting me. I’m in the middle space between perceived urgency and the wisdom of slow medicine.

Too quickly into surgery, when a newly diagnosed trial could be considered. Or starting temozolomide for recurrence when beginning therapy may disqualify someone from a promising trial. Even considering treatment at all when the best goals for care may be comfort and the completion of one’s life. These are reasons for patience.

So, no, I don’t think we should be starting treatment right now. Soon yes, but what is soon? Exploring options, yes. Considering second opinions, yes. Openly discussing pros and cons with a variety of both board certified professionals and patients with lived experience, yes. And these are the things we are doing!

The Vexed Question

I thought we’d be doing something treatment related by now, and I’m frustrated that we’re not. Even though, I don’t think we should be. The vexed question that long term survivors face is when to infer that a clinician’s willingness to take things steadily but slowly is a sign that the patient’s health can tolerate the wait or whether health care’s overburdened system demands that it does.

These are tension points in the care of people with complex illness, especially when that illness presents an existential threat. As soon as I saw that November 1 scan I was ready to advocate for

tumor treatment. I've lived with high grade glioma since June 2016, by the statistics alone, shouldn't we be treating this like tumor? Yet, it's February 18, and despite the additional tumor growth, I continue to work, write, co-parent, shovel the snow off the driveway, and even participate in a research study that required three, two hour scans. We had the time to be patient. How much longer will this be true?

Uncertainty and Unanswerable Questions

Since November, recommendations for my care have included surgery, gamma knife, and traditional radiotherapy, and these options have been recommended with and without chemo. When it comes to chemo, at least four options have been on the table; two approved for treatment of high grade glioma and two not yet approved for this indication. I guess it should be said that the mass itself detected on imaging has been identified as meningioma, recurrent glioma, and simply necrotic tissue. With the recent scans and addition of an agent that detects malignancy, we've now concluded that this is recurrent glioma.

For more than three months, we've lived with poor radiographic findings, three different proposed pathologies, and several different treatment options.

Should we have pursued any of those combinations of therapy, would the tumor be responding right now, as we speak? That we have not yet pursued one of these treatment plans, are we only providing a window for the cancer to continue infiltrating my brain? Or, by not rushing, have we spared me, say, a craniotomy, and we're pleased that we avoided an invasive procedure, when the tumor already shows signs of diffusion, which would be occurring, surgery or not, and I'd have undergone a tough surgery only to be ineffective to treat the spots of suspected tumor scattered like satellites around the central mass.

So yeah, I thought we'd be doing something by now. I'm frustrated we're not. And I'm relieved that we haven't. Welcome to my personal indecision 2024.

"Something Seriously Wrong"

Patients have risk factors for all sorts of diseases. Some of these include preventable lifestyle factors, others are identified by genetic tests for heritable mutations that increase the risk of cancer or other pathogenesis, and some factors include environmental exposures to things like toxins and known carcinogens.

A lot of cancers are just plain biological bad luck.

I've got one of the bad luck kinds. All the way back in the very end of 2014 I began having seizures. Longtime readers of Glioblastology know this story. While we were going through several tests and specialist visits to diagnose these dizziness episodes (and by extension, my brain cancer), a clinician remarked on my functional good health, "Adam, if there were something

seriously wrong with you, you'd be in much worse shape."

Of course, I was in worse shape. It would take another six months after that appointment to get an MRI. I'm in relative good shape with a serious thing again now. The pattern is unsettling.

It's the whole, "If it weren't for my brain cancer, I'm in really good health," joke I keep telling. But it's true. After all this recent testing, blood work, stroke work up, etc., what we've confirmed is that my joke isn't a joke at all, it's a description. I really am in really good health, but this tumor is growing, my symptoms are worsening, and we're taking our sweet time before taking action. Whether that's the best course of action or not, each day I'm back in that exam room from around winter 2015 when I was told that I didn't have anything seriously wrong with me.

Reliving that experience in real time while waiting again for clinical action, even if it was the best course of action in both circumstances, doesn't make it any easier to tolerate. Quite the opposite.

Let me make it clear: I don't think we should be starting treatment right now. But soon, and when is soon? Waiting for "soon" means near daily distress. Sometimes the patient experience has less to do with being a patient and has all to do with being a person, and people hate waiting.

Epilogue: Awareness to Advocacy

What is to be done? Let's continue funding research in the following areas:

- Improved imaging techniques to better identify tumor growth, tumor burden and distinguishing tumor from things like inflammation, necrotic tissue, or blood artifacts

- Bringing liquid biopsy research from the bench to the bedside to detect tumor burden by blood or cerebrospinal fluid

- Engaging palliative care as a component of the standard of care to support patients with disease-directed therapy and mental, emotional, spiritual and financial support while doing so

- Enacting better disability and health policies that allow patients to take a break from work without risking their livelihood to focus on the things that help us navigate periods of wait and indecision

Uncertainty and patience are skills that everyone struggles to cultivate. Addressing this difficulty

belongs in everyone’s treatment planning, even when, especially when, the plan of care is not yet defined.

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