Scans, Anxiety and Stability: Not What You Think

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Stable isn't as great as you think.

Stable is the best possible outcome.

Is the best possible outcome something to celebrate? Probably, yes.

Is the best possible outcome something that you hope for? Definitely, yes.

Is the best possible outcome a great thing? Only sort of.

Recently I've been telling cancer secrets. One of them is this: I'm not dead, and that's weird. Here is another, I don't really like talking about MRI results, and I suspect that I'm not the only one who feels this way. It is difficult, if not impossible, to imprint on others the what-it's-likeness of cancer, in my case, brain cancer.

As of 10:41am EST, April 7, 2021, 401 Facebook friends and followers liked my status update reporting that our MRI scan on April 5, 2021, indicated no recurrent disease. This result is, you guessed it, the best possible outcome. And thank you to our social network for wrapping us up in your arms and embracing our family.

What is recurrent disease? In the setting of cancer, it is a disease that has grown back after treatment, also called recurrence. Brain cancers like glioblastoma are understood to recur at an extremely high, near universal, rate. Glioblastoma is very treatment resistant, and this is even more so after recurrence. Many of our trusted treatment modalities like radiation therapy and chemotherapy damage DNA, and this DNA damage kills cancer cells, but it comes at a cost: chemo- and radiotherapy are associated with additional cellular mutations that could make recurrent disease even more recalcitrant; more treatment resistant. The newly diagnosed survival rate for brain cancer is already grim, and survival rates for *recurrent* brain cancer plummet.

And so, those of us in this patient population endure MRI scans on four, eight, or twelve week intervals to monitor our disease and hopefully catch recurrence as early as possible to increase

the window for early intervention or clinical trial enrollment. Lower grade brain malignancies may have a slightly more optimistic prognosis, but even with the lowest grade brain cancers and non-malignant brain tumors, MRI scans are routine, if only once a year, rather than once or twice each quarter.

No evidence for recurrent disease is the best possible outcome. It is something we celebrate; something we hope for, but it is not as great as you think.

The distress of these scans cannot be overstated. I have coped with scan anxiety, *scanxiety*, by reminding myself that whatever is happening inside my head is happening whether we look or not; the MRI is only a peek inside the window, but it doesn't change what is going on inside. And yet, it is challenging to not live or die by brain scans. The only other real measure we have for monitoring our disease is by functional measures, like fatigue, language, memory, and physical impairments, neurocognitive performance, and other symptoms and adverse effects. Many clinicians prize thorough physical and neurological exams with as much credibility as MRI images.

"How do you know how I'm doing?!" a friend asked her neuro-oncologist after they admitted that they typically do not review her scan until during or after the visit. "Well, I look at you!" the physician replied. This common sense answer is not altogether satisfying when there is so much protocol packed into the MRI procedure, but it's good to remember: For us patients, our functional health and quality of life is what we're interested in. When we first met my neurosurgeon, he told us, "I cannot believe the person who I'm talking to right now is the same person whose scans I just saw in my office. He was struck that despite the large mass in my brain, my cognition seemed otherwise intact.

Still, intellectually accepting a piece of clinical evidence like this one–that scans and function are not perfectly correlated–is not the same as accepting something with your entire body, and this is important because anxiety is in the body. The *thinking* brain tells us that an MRI scan is a diagnostic tool to aid clinicians in treatment planning, but the MRI procedure as an *experience* includes a hard table, a cold room, an IV wired up to an auto-injector that rapidly pushes contrast agents through the bloodstream to generate images of the vascular system, that creates pressure in the veins, a strange taste in the mouth, and a cooling sensation throughout the body; and the loud noises, the revealing hospital gown, all of this is the anxiety of a scan that has nothing to do with what you *think* about it; it's what you *feel* about it. And the existential threat of brain cancer is the threat that triggers your fight or flight, but the threat isn't visible, and there is nothing to fight against or flee from, except your own body.

This is the secret. I sort of disdain the public congrats for stable scans. I understand how cynical and crass this may strike you. No doubt that all 401 of you liked our update authentically, with true joy and celebration. And we feel that, too, but here's the thing: "No evidence of recurrent disease" may soothe the thinking brain, but what cancer patients are feeling cannot be healed with words on a page, but only through comfort and safety for our bodies. Maybe this is why virtual care delivery is difficult for many patients, and certainly it is why COVID hospital precautions to mitigate risk through limiting visitors feels so cruel, our bodies are left wanting for a

healing touch.

My therapist begins each session by directing me to place my feet comfortably on the floor, to feel the weight of my body in the seat, and to notice the sensations, beginning with the top of my head, and scanning my body to the tip of my toes. When your very existence is endangered, few things may help you feel more human, more grounded, more alive, than checking in with your body. My advice: Do not let a scan, whether good or bad results, stop you from fully living in your body. Health and wellbeing has little do with scan images.

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