

Regarding My Brain Cancer Recurrence, All I Know Is that I Just Don't

The longer you survive brain cancer, the less data we have to bring to bear on your medical decisions.

February 22, 2024 By [Adam Hayden](#)

"All I know is that I don't know. All I know is that I don't know nothing!"

—Operation Ivy, "Knowledge," 1989

Today I cried, I mined a government database service for Requests for Proposals to prepare a daily report for the Sales team, I ate a corned beef sandwich (rye, brown mustard), I spoke to great friends, and, with a preeminent neuro oncologist, we re-evaluated the medical news that made me cry in the first place, then I cried again.

Whitney was along for all of this, well, not the Sales report stuff, and she had a reuben, but most of the rest of it yeah. Our hearts felt like they kept breaking today, until they didn't feel like that, and now I suppose we just feel tired.

What I want more people to know about brain cancer is to appreciate the volumes of information that we just don't know. The longer you survive, the less data we have to bring to bear on your medical decisions. In the words of the radiation oncologist we met with today, not a novel piece of information for me, "We don't have a standard of care for recurrence."

In brain cancer patient advocacy, we often direct our awareness raising efforts toward the reality that for the treatment of brain cancer, the FDA has only approved four drugs and one device in the last thirty or so years. A drug approved in the mid-1990s is still the first line chemotherapy for this disease, and the next up goes back to the mid-1970s. Too few brain cancer drugs reach their clinical endpoints, meaning the goals of efficacy for a drug to warrant its approval are rarely met. Common endpoints are overall survival (OS) and progression free survival (PFS; the amount of survival with disease in a stable state). Whether PFS is a true surrogate endpoint for OS seems a little less compelling these days, but at any rate, with respect to the safety profile, patient tolerance, cancer response, and durable response rate (how long does the cancer respond to the investigational treatment), we don't find very many drug candidates to even subject to trial in pursuit of the coveted increase in OS.

So yes, too few therapies, not enough money directed toward drug development, and, only being descriptive here, we don't have enough patients that live long enough in the first place to generate longevity data to develop standard clinical guidance for long term survivors. In other words, "We don't have a standard of care for recurrence."

Solutions for several of these issues are in the works, like "natural history studies," large registries that amass thousands of patients and track them over time to generate much needed clinical data. We are suggesting new clinical endpoints that may expedite drug approval in the setting of brain cancer. We continue to learn from effective agents used to treat other cancer types, like a leukemia drug that inhibits a common gene mutation also present in brain cancer. Through philanthropy and biopharma startups, the research community is learning to leverage traditional fundraising with venture capital to fund research. My own ethical concerns notwithstanding for the latter.

We are genetically sequencing more patients and building the infrastructure for more databases to compile this data and make it available for research. The federal government is building its own data standards and infrastructure to facilitate the secure exchange of electronic health information so that patients have access to their data. Thanks to the CMS (Centers for Medicare and Medicaid Services), the ONC (Office of the Coordinator for Health IT), and the National Institutes of Health National Cancer Institute and Office of Data Sharing, not to mention Biden's Cancer Moonshot Initiative 2.0, housed in the White House Office of Science and Technology Policy, our government is investing in needed research and tools, but at the end of the day, survival rates from our most recalcitrant cancers remain low. For brain cancer, survival rates haven't changed in decades.

This feels esoteric until you're living with the disease. We're back to the central problem: We don't have a standard of care for recurrence. Like a friend said on the phone today when discussing treatment planning, "Everything is a huge chart of 'if-then' statements," meaning if you do this, then what do you expect? If you choose chemo, then which agent, or if you pursue radiation, then is it gamma knife or XRT? If you have a bad scan, then how long do you wait before the next? If you do nothing, then what will happen? Weighing this many factors with the diverse clinical judgment of physicians, solid agreement between them is rarely reached, more like consensus; like which avenue has the most support and which the least? With recurrence, your treatment plan is whatever the most recent doctor told you it was.

Not only do patients, like we did today, stare at several images of the brain, dotted with suspected cancer, some we say for sure is tumor and others we could say we aren't yet sure, we then must hear one plan from one doctor and another plan offered by another, and somewhere in the middle of that you have dinner with your kids and tell them ... something. But what? "Dad may be having radiation again, and that may make him feel not so good."

I don't mean to paint such a gloomy picture, but indeed the horizon is foggy. When I reflect objectively, when I apply my intellectual tools, I can reason my way into clear next steps, a calm demeanor, and realistic outlook for the future. But when I quiet my mind and allow my body to speak, the emotional turbulence of a day like today is exhausting.

Days like today have been more the norm recently. All I know is that I don't know. All I know is that I just don't know.

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