

Do You Know the Difference Between a Disease and an Illness?

To understand the brain cancer patient experience, writes Adam Hayden, learn to tease apart the biology from the experience.

July 29, 2024 By [Adam Hayden](#)

This post also appears on the National Brain Tumor Society [blog](#) in recognition of Glioblastoma Day of Awareness.

To best understand the brain tumor and brain cancer patient experience, we must differentiate between these two intimately related yet distinct features of living with a life-altering condition: disease and illness.

I was diagnosed with glioblastoma in June 2016 while completing the graduate requirements for my master's degree in philosophy. When I say "completing," I mean this literally. My spouse, Whitney, snapped pictures of me, donning my gown, sitting up in my hospital bed surrounded by notebooks, completing one of my final papers. The month-long stay in a rehab hospital to relearn to walk, bathe, feed and dress myself following an aggressive surgery to resect a large primary brain tumor offered plenty of study time.

It's probably owing to this strange, frightening, difficult time in my life that my response to my diagnosis was to treat it like a new research question. Equipped with my (online) University library access as a grad student, I dove into the brain tumor literature, mining sites like [PubMed](#) and journals like [Neuro-Oncology](#) to try and understand my disease. No surprise that a few weeks in a hospital wasn't enough time to get up to speed on the peer-reviewed literature! I should say that I've never stopped studying!

One of the many reasons that I am so committed to NBTS is because of the terrific science we've funded and researchers who are collaborative partners in groundbreaking programs like our [DNA Damage Response Consortium](#), or DDR Consortium. We see this commitment to putting science to work and serving the community, with our new [MyTumorID](#) Campaign.

These days, I consider myself "conversationally competent" in brain tumor science. And by this, I mean that I'm about as knowledgeable on this subject as your die-hard Buffalo neighbor knows about the Bills Mafia. We wouldn't let the dude coach the team, but he's got Trivia Night in the Bag.

While I was still learning to pronounce phrases like intratumoral heterogeneity, I recalled an upper-level undergrad course I had taken a few years prior, Medical Humanities. Skimming through old notes from this class on a shared drive, I stumbled on a topic, Narrative Medicine. It turns out, what I found there would be the guide to navigate my diagnosis.

One of the ideas came from physician, author, and professor, [Arthur Kleinman](#), whose book, *The Illness Narratives* (1988), utterly reframed my understanding of my diagnosis. I learned a penetrating insight early in my disease trajectory: There are disease problems and there are illness problems. I had been spending all my time on disease problems and not much on the illness problems. To best understand the brain tumor and brain cancer patient experience, we must differentiate between these two intimately related yet distinct features of living with a life-altering condition: disease and illness.

Kleinmann describes it like this, paraphrasing, patients present to their physicians with illness problems, including disjointed symptom reports, worry about work and childcare, a few words about their medical history or family history, and maybe distress about possible diagnoses they Googled. The physician then translates those illness problems into a narrow set of technical issues as, you guessed it, disease problems.

That distinction between disease problems and illness problems is profound. It helps to explain many routine experiences for patients with cancer. Scanxiety, for example, the anxiety we experience around MRI scans, benefits from this treatment: The scanner works to produce images of a bunch of cells to monitor a tumor. What does that sound like? Yep, that's a disease problem. But the worry over what those images may show? Illness problem.

When the surgeon sent to pathology a small sample of the tumor tissue removed from my brain during resection to begin the process of diagnosis, that was a disease problem. When I sat holding Whitney's hand to hear that diagnosis, then called close friends and family to share the news, those were illness problems.

When I was admitted to that rehab hospital for intensive therapy so that my brain could form new pathways as I learned to walk again, disease problem. When I learned to cope with being alone in a locked brain trauma unit at that hospital with my family on the other side of the city, illness problem.

In February of this year, when the PET tracer combined with recent MR imaging led the medical team to confirm recurrence of my brain cancer, disease problem. Hearing that "a couple more years" was the optimistic prognosis, illness problem.

And here's the deal with some of your communication to us patients, like when you forward any clickbait headline of a new brain cancer treatment, what are you sharing? You're sharing disease literature with us! It's not that we aren't interested or appreciative, but what does that news article do to address our illness problems? Loneliness, uncertainty, fear, depression, and anger are rarely soothed by the medical reporter's writeup about a new immuno-oncology trial. Instead, prioritize presence, bear witness to our suffering, sneak into the hospital some matzah ball soup

from the deli up the road that only serves this panacea on Fridays. That's how you address an illness problem, and this is what patients and their care partners need the most!

While I've expanded Kleinman's insight beyond its original scope, I would hope he's happy enough with what I've said so far. I think the lesson in all of this is to tease apart the biology of a thing from the experience; the biology from the biography, I've heard some say. That is how to best understand the patient experience, and that's what I'd like you to know on Glioblastoma Awareness Day. Now get out there and support your loved ones with their illness!

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