I Have Brain Cancer, and I'm Eating Ice Cream

Yes, nutrition and diet can impact my cancer outcome, but so can a sense of agency over my cancer treatment.

December 7, 2023 By Adam Hayden

On Thursday, June 20, 2019, I wrote a post titled, "You Might as Well." That title came from a comment made by a Radiation Oncologist who, when remarking on my strict diet, said, "Go home and eat some ice cream, you might as well." When Whitney and I met with a neurosurgeon this week, that experience came rushing back. In today's post, I argue that patient-centered care, respecting the whole person, is critical to patient wellbeing. Let's get into it.

You Might as Well

Framing up my response to this "advice"—that I might as well eat some ice cream—I wrote, in 2019:

> "[F]ollowing the deterministic ideal from biomedicine, that diseases are governed by microscopic physical laws, and that what matters to care is what happens in the clinic, health outcomes and prognosis follow a disease trajectory that is well established through population-wide statistics. Because the outcomes for my serious illness are grim and options for curative therapies are limited, the take on self-care is "anything goes." Go eat some ice cream. You might as well."

To put my words in a more straightforward way: What I critiqued in that post was/is the inclination of physicians—at least that physician—to discount a patient's ability to alter the ultimate outcome of their diagnosis through supplemental strategies like nutrition modifications. I was floored by the suggestion that I might as well ditch the diet I was following and simply eat some ice cream.

Now I have a lot to say, reflecting on that post from four and a half years ago. In one respect, maybe that doc was right: Enjoy life, I could imagine him saying, and in the wisdom gained through seven-and-a-half years living with brain cancer, I'm much less offended by his remark today. While I don't think his evaluation respected the goals and values that mattered to me then, I am more sympathetic to the overall thrust of his guidance. More on this in a moment.

In other respects, reinforcing my initial frustration, we in fact have taken strides in better understanding how environmental factors influence patient outcomes. The rise in Social Determinants of Health (SDOH) research shines a light on the tremendous influence that a person's zip code has on their health—even more so than their genetic code. And with respect to diet specifically, nutrition science is playing a greater role in healthcare. Just last month, the Journal of the American Medical Association, or JAMA, reported:

> "The findings of this study suggest that a combination of an energy-reduced Mediterranean diet and physical activity mitigates the potential negative effects of age-dependent changes in body composition; continued follow-up is warranted to confirm health consequences in the long term."

Things like food deserts that prohibit access to fresh and healthy foods and poor access to health care are environmental factors that absolutely influence patient health outcomes. Maybe we should not simply, "eat some ice cream."

A couple of scoops on a warm Sunday afternoon, sure, but not at the expense of an overall lifestyle of whole foods and physical activity. And in fairness to that radiation oncologist, it's pretty uncharitable of me to generalize his off-the-cuff comment as though he were recommending that I abandon all health strategies. I think he spoke with general goodwill: Hey you skinny kid with brain cancer, let the nutrition optimization go and pick up a pint of Ben and Jerry's.

That's fair.

A Partner in My Own Care

The miscalculation made by that clinician four years ago was informed by the prognostic indicators that were the source of truth at the time: Glioblastoma kills within two years. In June of 2019, the time of that encounter, I had recently recognized two years of survivorship. By everything that medicine knew about my disease, my days were numbered. "Eat some ice cream. You might as well." In that context, his comments make a little more sense.

But let's also look closer—things snap into focus when viewed through the rearview mirror. My anger with that physician's comment was rooted in defiance. I will not eat ice cream. I wrote a loosely related post in September of the same year called, "Health as Resistance." The most punk rock thing I could think to do was point a middle finger at the statistics and not merely "eat healthy and exercise," but to pour over nutritional protocols and read everything I could find about cellular metabolism and mitochondria. I glance across the room today, and the books I read about mitochondria and glycolysis, about diet protocols, about the role of dysregulated metabolism as a hallmark in cancer still dot my bookshelf. I didn't merely want to be healthy through cancer treatment, I wanted to become competent in the pathways and cell signaling that accompanied carcinogenesis, or the origin of cancer in the body. The doc's recommendation was not only negligent of my experience, it struck me as flying in the face of my role as a partner in my own care.

Authentic patient-centered care demands that a patient’s knowledge of their condition and agency with respect to treating that condition is as important as gathering previous medical history.

This is really at the heart of things: Do I think every patient should read books that are more appropriate for undergraduate molecular biology than the waiting room? No, but do I think patients generally bring a wealth of experience to each clinical encounter, yes, and authentic patient-centered care isn’t satisfied by a phone survey that asks whether you felt your needs were addressed. Authentic patient-centered care demands that a patient’s knowledge of their condition and agency with respect to treating that condition is as important as gathering previous medical history.

Let me put it this way: Whether a diet protocol would materially impact my cancer care was downstream from the real issue: Do you see me, hear me, and understand me as a person with agency, experience, wisdom, and motivation to be your partner in treating my disease and not the passive subject who is compliant in following doctor’s orders.

My lifestyle became the surrogate marker for the sense of agency that I felt in an otherwise out of control period in my life.

I’m Eating Ice Cream

“Do you prefer to see your weight in pounds or kilograms?” the nurse asked as I stepped onto the scale. “Oh, I don’t care,” I replied somewhat dismissively, somewhat smugly. In fact, I regretted that as soon as I said it, it was rude of me to be dismissive. I could have laughed it off, “After so many doctor’s appointments, I know the back of the envelope conversion for kilograms to pounds, so however you have it set is fine,” or I could have apologized right away, with vulnerability, “I’m a little distracted with this appointment with the neurosurgeon, and I’m sorry that I replied with a rude tone. That’s unlike me.” I did neither. “Oh, I don’t care.”

The truth is that I didn’t want to see either kilograms or pounds! I didn’t want to be on the scale at all. In the past four or five years I’ve gained around 40 pounds. I gave up the strict diet that I had been following—the one that prompted that 2019 blog post. I stopped going to the gym. I stay up too late, and I have too many beers out with crew.

In short, I’ve been eating ice cream.

I was at the neurosurgeon’s office to hear his opinion on the new lesion spotted in my brain

following the last MRI. If lifestyle is a surrogate marker for my own agency, then allowing my lifestyle to unravel speaks to my own (perceived) loss of control. I clinged to health as resistance, but now I've capitulated. Maybe it's the exhaustion of seven years with brain cancer, seven years with routine MRI scans, seven years of impairments and seizures, seven years of not driving, seven years of watching members of our community be diagnosed, go on clinical trial, then die. Of course, there are long-term survivors like me, and I embrace my role to be a long-term survivor to our community; to show it's possible. But, friends, it's exhausting.

It's from the exhaustion that, I guess, I gave into the "might as well," attitude, but I'm not a might as well sort of guy. I'm a read-everything-you-can sort of guy. I'm a middle-finger-to-the-statistics sort of guy. I'm an aging punk rocker and recognized public speaker. Strangely, I think it took a few scoops of ice cream to show me that—to show me that I'm bigger, better, and more deserving than "You might as well."

When the resident walked into the office to go over my MRI scans this week, he asked what I knew about what was happening. I told him exactly what was happening: The lesion, the radiologist's impression, the conclusions of the tumor board—miss me with that passive patient bullshit. I'm an active partner in my care. I think tonight I'll skip the ice cream.

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