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## Cancer and the Time of Waiting

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## Cancer and the Time of Waiting

### Cover Page Footnote

The author extends thanks to Zomi Bloom, whose comments on the first draft improved it greatly as her conversations improve my ability to understand my own experience greatly, and to Eileen and Kate, who shared their experiences with me as I shared my experiences with them. He also extends thanks to Julia Brown, Suzanne Black, and the editors and reviewers.

## Cancer and the Time of Waiting

*I remember her...*

*...waiting for me in the school parking lot*

*In our old blue station wagon*

*When whatever it was I was practicing for*

*Ran late....*

*And I remember her waiting for me*

*At the airport when I got back from Japan,*

*Waiting for everything to be all right,*

*Waiting for her biopsy results.*

*“Waiting” by George Bilgere<sup>1</sup>*

### Waiting for Cancer

In 1956, in “On the Origin of Cancer Cells,” Otto Warburg tried to pin down the causes for the “mysterious latency period of the production of cancer.”<sup>2</sup> Fifty years later, in “Genetic Progression and the Waiting Time to Cancer,” Beerenwinkel, Antal, Dingli, Traulsen, Kinzler, Velculescu, Vogelstein, and Nowak<sup>3</sup> replace the “mysterious latency period” with talk about a waiting period: they set out to “derive an analytical formula for the expected waiting time for the progression from benign to malignant tumor.” They started with a “normal” cell and predicted the number of mutations the cell will undergo. Based on the number of mutations, they could calculate how long it will take for a normal cell to produce a benign tumor *and* how long before those mutations produce a tumor that becomes malignant. The length of the wait depends on genetics; your cells may be more or less disposed toward mutation than mine. The length of the wait depends on the location of the cell in the body (colorectal cells have different mutation rates than lymph cells).

In these mathematized models, cancer isn’t something to avoid. Good diet, exercise, meditation, retreating to a mountain cabin far from carcinogens in the air, the food, the water -- these choices aren’t part of the calculation of cancer for these doctors, because cell mutation is inevitable, and so cancer is inevitable. You don’t avoid cancer; you wait for it. You may die before you are done waiting; you might be killed in a car accident at a young age, or you might die of a heart attack at ninety. In both cases, you die never having had cancer. But if you had lived a little longer, cancer would have eventually come.

Cancer is defined by waiting. The experience of cancer is defined by waiting.

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### Waiting for Diagnosis

In 2007, Mom *almost* received the bad news over the phone. The clinic staff would not share her results over the phone. If there were nothing wrong, presumably, she would have received a cheerful “all

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<sup>1</sup> “Waiting” by George Bilgere in *The Missouri Review*, Volume 24, Number 3, 2001, pp. 58-59.

<sup>2</sup> *Science* Volume 123, Number 3191, Feb. 24, 1956, pp. 309-314: 310.

<sup>3</sup> *PLoS Computational Biology* Volume 3, Number 11, 2007, pp. e225.

clear” over the phone. She was asked to come in. Immediately, in her brain and in mine, the only question remaining was *what kind of bad news* we would hear.

My friend K and I drove to Milwaukee from Duluth, MN. It’s a seven-hour drive, but I drove twenty over the limit. The faster we got there, I believed, the faster we could start doing something.

There was no reason to rush. The doctors needed to complete a battery of tests to ensure the right diagnosis and appropriate course of treatment. Those tests would come slowly, as the clinic could schedule them. But even beyond that slow search for diagnostic data, there just wasn’t a rush.

Pancreatic cancer killed my grandfather and it killed my stepfather; it killed them both when I was too young to understand. The time between diagnosis and death was measurable in weeks. Their deaths were my only intimate experience of cancer, found in their bodies when it was too late to help. So: I wanted us to start treatment now. I believed that every minute counted.

But before we could act, we needed multiple tests to determine that my mom was diagnosed with stage three breast cancer. The news threw my mom into shock. While she was numb with the news, I was worried. Perhaps, my mind raced, we were moving so slowly toward treatment because it was too late for any course of treatment to matter?

Perhaps my place in this story was limited to driving as fast as I could. Now that I was there, I had surrendered my position in the story to waiting. Philosopher Raymond Tallis tells us that when we are waiting, “we surrender our position at the centre of the universe... The narrative of our lives sometimes seems like a densely woven network of ‘not yet.’”<sup>4</sup> I was entangled in the not-yets, my flailing only entangling me tighter.

### **Waiting for Treatment**

In 2017, my friend K began piecing together her diagnosis in phone calls and test results on her “patient portal” website. There were “microcalcifications.” The microcalcifications were not cancer, but they were an indicator of cancer. More tests needed to be done.

In the meantime, at home, there was aggressive Googling. In the era of *WebMD*, there is little a doctor can say that can’t be threaded together into diagnosis and prognosis. Sometimes, I wished that the pictures I assembled were wrong. I sat in the waiting room outside the doctor’s office hoping to be wrong. I sat in the exam room, waiting for the doctor, hoping to be wrong.

When the diagnosis was shared, we began the waiting.

K and I, we’d done that waiting before, with my mom. But we were still unprepared. We, I, still wanted to act: scheduling appointments quickly, in clusters, as close to back to back as possible. We met with the surgeon, the oncologist, the radiation oncologist, and two plastic surgeons. We called for each appointment with a sense of urgency, but the days or weeks until the clinic staff could find openings appeared no faster.

We waited for the tests. We waited for the results. We waited for the opinions about the results to coalesce in tumor board meetings on the following Thursday morning. We waited for more than a month from diagnosis to the decision, and then we waited for the surgery.

K was diagnosed at stage one based on scans and mammograms. We were warned that the assessment of the stage could be changed after the mastectomy, as a sentinel lymph node would be

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<sup>4</sup> “On Waiting” from *Philosophy Now* Number 96, May/June 2013 ([https://philosophynow.org/issues/96/On\\_Waiting](https://philosophynow.org/issues/96/On_Waiting)).

removed to check for spread. But we had a sense of relief in early detection. We thought that we had caught it early enough that action would very likely save her life.

There was still no rush to act. My mom was diagnosed at stage three and there was no rush to act. My friend was diagnosed at stage one and there was no rush to act. The nature of the diagnosis [breast cancer] did nothing to create urgency. The stage of the diagnosis [an indicator of its spread within the woman's body] did nothing to create urgency.

But for me, a week between tests was interminable. The weeks between the mammogram and start of treatment [surgery, then possibly radiation, then definitely chemo] were half of all the time my grandpa had left in the world after his pancreatic cancer diagnosis. I felt powerless, bordering on hopeless.

Chike Okoye tells us that "In situations of hopelessness, the seeds or kernels of positivity and greatness could well-nigh be nestling in potentiality, waiting to act." But I must be at peace with that potentiality, something I can do, Okoye says, "as long as the self is subsumed and there is no irritable reaching out for facts and solutions."<sup>5</sup> Waiting for biopsies and scans and blood tests, I craved facts and solutions where there were none. I craved a sense that *I* was doing everything that could be done -- against Okoye's exhortations to subsume the self. I hear his words; I hear his exhortation to find seeds and kernels of positivity in the hopeless in waiting.

But can't we start chemo faster, anyway?

The experience of cancer has been defined by waiting, and I'm struggling to cope with that experience.

### **Waiting for Failure**

The signals that cancer has arrived are diverse. For my mom: her nipple began to turn inward before she went to seek medical help. [Her insurance was primarily for catastrophic care; she was afraid of the costs. Maybe, a little, she was also afraid of the truth she would learn.] For K, the microcalcifications were only visible on a mammogram. Microcalcifications are spectacularly early detection.

But for both of them, the cancer had been present before we could see it, for both my mom and for K. Cancer visits the body before we can detect it. It begins one cell at a time, and we lack the technology to detect cellular changes.

It would not help to detect cancer at its first appearance. Often, when cancer first visits the body, the body fends it off. "Indeed, it is possible, even likely, that your immune system may regularly fight off cancer or pre-cancer on a regular basis without you even knowing it." The first time cancer is found in a mammogram or a self-exam may not be the first time it exists in the body. It may have visited and our immune system may have removed it from our body. According to Dr. Alan Tan, "We all have a mechanism to filter out a small amount of cancer cells to prevent us from having visible cancer in the body... Over time, that balance becomes lost."<sup>6</sup>

Sitting in the oncologist's exam room, my loved one in a hospital gown, waiting for the doctor to arrive and tell us which of the painful procedures will be first, my mind races. We wait for cancer. We

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<sup>5</sup> C. Okoye, "The Sisyphean Myth, Negative Capability and Societal Relevance." *OGIRISI: A New Journal of African Studies* Volume 11, Number 1, 2015, pp. 113-120: 118.

<sup>6</sup> Cancer Treatment Centers of America, "How Does the Immune System Work? When it Comes to Cancer, it's Complicated." October 19, 2017 (<https://www.cancercenter.com/community/blog/2017/10/how-does-the-immune-system-work-when-it-comes-to-cancer-its-complicated>).

wait for our immune system to fail. We wait for the oncologist and radiologist and surgeon, but we hope for better news, this time.

### **Waiting in Itself**

Beerenwinkel, one of the researchers who teaches me about the waiting period for the appearance of cancer in an organism, in a person, engages “computational biology,” the study of cancer from an evolutionary perspective. He tells me that “cancer research involves a range of clinical, epidemiological, and molecular approaches, as well as mathematical and computational modeling.”<sup>7</sup> These mathematical approaches tend toward some abstraction: they predict the behaviors of a cancer long after the person enduring the cancer no longer walks this earth. I can run a mathematical calculation of how long it might take me to walk to work tomorrow [about forty minutes, longer maybe because the route is uphill]. I can run a mathematical calculation of how long it might take me to walk to the center of the sun [somewhere between three thousand and four thousand years, if my shoes last -- the last thirty five years of that walk would be within the sun itself, which would likely melt my shoes.

That’s not a journey that I would want to make.

In every consultation about cancer, the doctors carefully avoid combat imagery. My mom, my friend, they are not “battling” cancer; they are on a journey. Where the journey leads, we don’t know. We hope it leads toward healing, but we don’t know where the journey through surgery, radiation, and chemotherapy will lead.

Perhaps this experience of a journey with an unknown end helps me rethink my experience of waiting. Heideggerian philosopher Barbara Dalle Pezze tells us that waiting does not always have an object; we are not always waiting for something. Sometimes, we wait with an openness for what comes: “If we ask what we are waiting for, we are expecting something, we already have an object of expectation, whereas we need to remain open towards something we do not know... In waiting something opens. What we need to do is ‘just’ wait, wait without expecting.”<sup>8</sup> *It’s so hard.*

I have spent so many hours in rooms designated for waiting. Each time, I know I am waiting “to see the doctor,” or “for my loved one to come out of surgery,” or “for an open chair in the infusion center.” What I’m waiting for is clear, and relief comes when the waiting is over. It’s difficult to let that go, to wait alongside my loved ones in a different way, open towards something we do not know.

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<sup>7</sup> N. Beerenwinkel, C.D. Greenman, and J. Lagergren, “Computational Cancer Biology: An Evolutionary Perspective.” *PLoS Computational Biology* Volume 12, Number 2, 2016, pp. e1004717. <https://doi.org/10.1371/journal.pcbi.1004717>.

<sup>8</sup> Barbara Dalle Pezze, “Heidegger on Gelassenheit.” *Minerva - An Internet Journal of Philosophy* Volume 10, 2006 (<http://www.minerva.mic.ul.ie/vol10/Heidegger.html>).