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SundayReview | OPINION

How Long Have I Got Left?

By PAUL KALANITHI JAN. 24, 2014

AS soon as the CT scan was done, I began reviewing the images. The diagnosis was immediate: Masses matting the lungs and deforming the spine. Cancer. In my neurosurgical training, I had reviewed hundreds of scans for fellow doctors to see if surgery offered any hope. I'd scribble in the chart "Widely metastatic disease — no role for surgery," and move on. But this scan was different: It was my own.

I have sat with countless patients and families to discuss grim prognoses: It's one of the most important jobs physicians have. It's easier when the patient is 94, in the last stages of dementia and has a severe brain bleed. For young people like me — I am 36 — given a diagnosis of cancer, there aren't many words. My standard pieces include "it's a marathon, not a sprint, so get your daily rest" and "illness can drive a family apart or bring it together — be aware of each other's needs and find extra support."

I learned a few basic rules. Be honest about the prognosis but always leave some room for hope. Be vague but accurate: "days to a few weeks," "weeks to a few months," "months to a few years," "a few years to a decade or more." We never cite detailed statistics, and usually advise against Googling survival numbers, assuming the average patient doesn't possess a nuanced understanding of statistics.

People react differently to hearing "Procedure X has a 70 percent chance of survival" and "Procedure Y has a 30 percent chance of death." Phrased that way,

people flock to Procedure X, even though the numbers are the same. When a close friend developed pancreatic cancer, I became the medical maven to a group of people who were sophisticated statisticians. I still dissuaded them from looking up the statistics, saying five-year survival curves are at least five years out of date. Somehow I felt that the numbers alone were too dry, or that a physician's daily experience with illness was needed for context. Mostly, I felt that impulse: Keep a measure of hope.

These survival curves, called Kaplan-Meier curves, are one way we measure progress in cancer treatment, plotting the number of patients surviving over time. For some diseases, the line looks like an airplane gently beginning its descent; for others, like a dive bomber. Physicians think a lot about these curves, their shape, and what they mean. In brain-cancer research, for example, while the numbers for average survival time haven't changed much, there's an increasingly long tail on the curve, indicating a few patients are living for years. The problem is that you can't tell an individual patient where she is on the curve. It's impossible, irresponsible even, to be more precise than you can be accurate.

One would think, then, that when my oncologist sat by my bedside to meet me, I would not immediately demand information on survival statistics. But now that I had traversed the line from doctor to patient, I had the same yearning for the numbers all patients ask for. I hoped she would see me as someone who both understood statistics and the medical reality of illness, that she would give me certainty, the straight dope. I could take it. She flatly refused: "No. Absolutely not." She knew very well I could — and did — look up all the research on the topic. But lung cancer wasn't my specialty, and she was a world expert. At each appointment, a wrestling match began, and she always avoided being pinned down to any sort of number.

Now, instead of wondering why some patients persist in asking statistics questions, I began to wonder why physicians obfuscate when they have so much knowledge and experience. Initially when I saw my CT scan, I figured I had only a few months to live. The scan looked bad. I looked bad. I'd lost 30 pounds, developed excruciating back pain and felt more fatigued every day. My tests revealed severely low protein levels and low blood counts consistent with the body overwhelmed, failing in its basic drive to sustain itself.

For a few months, I'd suspected I had cancer. I had seen a lot of young patients with cancer. So I wasn't taken aback. In fact, there was a certain relief. The next steps were clear: Prepare to die. Cry. Tell my wife that she should remarry, and refinance the mortgage. Write overdue letters to dear friends. Yes, there were lots of things I had meant to do in life, but sometimes this happens: Nothing could be more obvious when your day's work includes treating head trauma and brain cancer.

But on my first visit with my oncologist, she mentioned my going back to work someday. Wasn't I a ghost? No. But then how long did I have? Silence.

Of course, she could not stop my intense reading. Poring over studies, I kept trying to find the one that would tell me when my number would be up. The large general studies said that between 70 and 80 percent of lung cancer patients would die within two years. They did not allow for much hope. But then again, most of those patients were older and heavy smokers. Where was the study of nonsmoking 36-year-old neurosurgeons? Maybe my youth and health mattered? Or maybe my disease was found so late, had spread so far, and I was already so far gone that I was worse off than those 65-year-old smokers.

Many friends and family members provided anecdotes along the lines of my-friend's-friend's-mom's-friend or my-uncle's-barber's-son's-tennis-partner has this same kind of lung cancer and has been living for 10 years. Initially I wondered if all the stories referred to the same person, connected through the proverbial six degrees. I disregarded them as wishful thinking, baseless delusion. Eventually, though, enough of those stories seeped in through the cracks of my studied realism.

And then my health began to improve, thanks to a pill that targets a specific genetic mutation tied to my cancer. I began to walk without a cane and to say things like, "Well, it's pretty unlikely that I'll be lucky enough to live for a decade, but it's possible." A tiny drop of hope.

In a way, though, the certainty of death was easier than this uncertain life. Didn't those in purgatory prefer to go to hell, and just be done with it? Was I supposed to be making funeral arrangements? Devoting myself to my wife, my parents, my brothers, my friends, my adorable niece? Writing the book I had

always wanted to write? Or was I supposed to go back to negotiating my multiyear job offers?

The path forward would seem obvious, if only I knew how many months or years I had left. Tell me three months, I'd just spend time with family. Tell me one year, I'd have a plan (write that book). Give me 10 years, I'd get back to treating diseases. The pedestrian truth that you live one day at a time didn't help: What was I supposed to do with that day? My oncologist would say only: "I can't tell you a time. You've got to find what matters most to you."

I began to realize that coming face to face with my own mortality, in a sense, had changed both nothing and everything. Before my cancer was diagnosed, I knew that someday I would die, but I didn't know when. After the diagnosis, I knew that someday I would die, but I didn't know when. But now I knew it acutely. The problem wasn't really a scientific one. The fact of death is unsettling. Yet there is no other way to live.

The reason doctors don't give patients specific prognoses is not merely because they cannot. Certainly, if a patient's expectations are way out of the bounds of probability — someone expecting to live to 130, or someone thinking his benign skin spots are signs of impending death — doctors are entrusted to bring that person's expectations into the realm of reasonable possibility.

But the range of what is reasonably possible is just so wide. Based on today's therapies, I might die within two years, or I might make it to 10. If you add in the uncertainty based on new therapies available in two or three years, that range may be completely different. Faced with mortality, scientific knowledge can provide only an ounce of certainty: Yes, you will die. But one wants a full pound of certainty, and that is not on offer.

What patients seek is not scientific knowledge doctors hide, but existential authenticity each must find on her own. Getting too deep into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability.

I remember the moment when my overwhelming uneasiness yielded. Seven words from Samuel Beckett, a writer I've not even read that well, learned long ago

as an undergraduate, began to repeat in my head, and the seemingly impassable sea of uncertainty parted: “I can’t go on. I’ll go on.” I took a step forward, repeating the phrase over and over: “I can’t go on. I’ll go on.” And then, at some point, I was through.

I am now almost exactly eight months from my diagnosis. My strength has recovered substantially. In treatment, the cancer is retreating. I have gradually returned to work. I’m knocking the dust off scientific manuscripts. I’m writing more, seeing more, feeling more. Every morning at 5:30, as the alarm clock goes off, and my dead body awakes, my wife asleep next to me, I think again to myself: “I can’t go on.” And a minute later, I am in my scrubs, heading to the operating room, alive: “I’ll go on.”

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