

SYMPTOMS OF CONSCIOUSNESS: WHERE SCIENCE AND STORY MEET

Lost in Translation

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In the Beginning

“Scleroderma,” the rheumatologist said after examining my stiff swollen arms and legs. “Unfortunately, given your biomarkers, it’s likely to get worse before it gets better, but you never know.” She gave a quick rundown of what I might expect—rapidly progressive skin and joint tightening, GI symptoms, high likelihood of multi-organ involvement.... “Let’s hope for the best.” She paused, then asked if I had any questions.

Nothing came to mind. Despite being caught off-guard by the news that I had a severe form of a dreadful disease, one that was likely to maim if not kill me, my normal play-by-play, moment-to-moment mental chatter was strangely absent. Having previously read about and seen a few patients with scleroderma, I had a strong sense of what to expect, but this knowledge was purely visceral—unaccompanied by imagery or words. I just knew.

After what seemed like an eternity, my inner voice rallied against the emptiness and fired off a salvo of questions, many of which had already been answered. For example, in response to the rheumatologist carefully explaining that the disease was so rare in men of my age that it was impossible to predict what might happen, I blurted out, “So what’s my prognosis?” Not at all what I meant to say. Not at all what I was thinking. Embarrassed, I shook my head. She nodded, prescribed immunosuppressants, and suggested a palliative care/pain management evaluation.

Only later, back in my car and replaying the consultation did I hear the proper translation of what I had been thinking since I heard the word *scleroderma*—oh my god, I’m going to die.

Getting Worse

My primary care physician asks, if necessary, would I want full resuscitation measures “in the event of...” He stops and looks at me as though it isn’t necessary to spell out what might go wrong. My nephrologist chimes in, would I consider dialysis in the event of kidney failure. My rheumatologist is next, but I interrupt her. “I know, ‘in the event of....’”

And so on, with each new complication.

Now (Two Years Later)

Despite lengthy hospitalizations for acute kidney injury and massive gastrointestinal bleeding and the expected progressive loss of use of my hands, not to mention a cornucopia of aches, pains, itches, and physical limitations, overall I am feeling better. My skin is softening, breathing is easier, and I can finally bend forward enough to yank on my socks (barely). Doctors are surprised but unsure whether these improvements are due to my medications, the natural history of my rare variant of scleroderma, or both. They are cautiously hopeful, but no one is willing to place a bet on my future—I am a textbook case of uncertainty.

So, How Do I Feel?

I tell myself and others that I am enormously thankful, glad to be alive, not doing so bad, fine thank you, have great doctors, could be worse.... I pluck ready-to-wear clichés from the surface of my mind while simultaneously appalled at the depth of my shallowness.

The palliative care nurse asks me how I feel about my prognosis. I say, “The future is vastly overrated.” Undaunted, she follows with, “Would you be interested in spiritual counseling?” “No thanks, I’m happily married.”

Friends marvel that I can still make fun of my circumstances. It is hard to explain that my bravado is absurdity and despair tightly holding hands in the waiting room.

There are flurries of ...apprehension? Discouragement? Resignation? Darker unmentionables? Spontaneous moments in the neighborhood of acceptance, as though the demons have gone on lunch break? Who’s to say? Certainly not me. My bedrock thoughts have a life of their own, perhaps nudged by language, but almost certainly not derived from it any more than are the thoughts of animals and newborns.

Having been constrained by illness plus avoidance of others during this time of COVID, I have had more than enough time to sit quietly and listen for deeper murmurings, but I have a tin ear. Words scrape against each other, jockey for position, struggle to understand what I am thinking. My father used to tell me that talk is cheap. He didn’t know the half of it.

I am lost in translation. I am bits and pieces, a kaleidoscope of contradictions. I am sunlight, clouds, wind rustling in trees, shadows, a deserted alleyway, darkness. I am Dr. Burton in the treatment room, Mr. Burton on the hospital wristband, no one in the big picture (a direct quote from my mother just before she died).

I am a stranger to myself.