<u>REFLECTIONS</u>

My body is a lantern: Oscillopsia and an experience of Ayurveda

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A name for a condition

February 9, 2017. The alarm on my phone was set to a predawn hour. We were to leave for a holiday in the hills, a long drive that I had planned for days, eager for hours of camaraderie with the steering wheel. But the waking was a shock. The walls and ceiling of the room were swirling, my body felt as if strapped to a rotating carnival wheel. Sitting, standing, walking, nothing eased it. I threw up from the nausea. Maybe it will slow, maybe it will stop, maybe it is nothing. It is vertigo, said my cousin (a doctor) on the phone, and prescribed an over-the-counter medication. The world steadied. I made the drive, the vacation, but the condition was now with me, for several hours each day.

A series of tests followed after the vacation, consultations with three ENT specialists, two neurologists, one orthopaedician. There seemed to be some consensus on the diagnosis of BPPV (Benign Paroxysmal Positional Vertigo). One longs for the word "benign" in the context of complicated health conditions that afflict us, but the word was a slight to a teacher of literature, a mockery almost. Benign: in other words, gentle and kind. This swirling of the world was neither gentle nor kind. In the days that followed, I also heard high pitched sounds for several seconds that nobody else did. Tinnitus, I was later told. I went through the Epley Maneuver, the timed turnings of the upper body, stayed upright in bed for a couple of nights, tried to be gentle with my head movements, prayed that whatever follicles had apparently been dislodged in my ear were now safely out of the way. I focused on walking steadily even as the world swayed, but reading and writing was punishment. It was a devastating thought for a writer and teacher. Emails became medieval torture devices. Anything that needed concentration and attention to detail was draining. Perhaps the condition remained benign, but soon there was nothing "positional" about it. Vertigo had been replaced by something else. Everything swayed, constantly, repeatedly, like an empty swing in the park played by the wind. Even when I lay down, even when I closed my eyes, the same sway. To others, I appeared perfectly fine and upright, a deceptive external normalcy,

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but these others were shifting in my vision. The direction of the sway would change, so also the tempo, and when the environs stilled, it felt as though the rocking was in me, entirely unpredictable. Back and forth, in and out, moving, moving, always moving.

Almost as frustrating as the condition was trying to share it with others. I felt restless each time vertigo became the suggestion or point of comparison, because I knew it was not the same. I needed a word, some way to tell why my body was not responding to vertigo medication or that the nowconstant instability of my vision was wearing me out. Strangely enough, being in a moving vehicle was easier, and someone said that perhaps the vibrations of the motor helped. But mostly the world shimmered, wavered, like those movie shots (to show disorientation) where two images overlap, blur at the edges. Often it was a clear oscillation of objects from one point to another. At times a shifting, a tremor, a great awareness of the spaces between all the things in a sphere of vision, and realising that they had edges that could pixilate at different momentums.

Oscillopsia. The neurologist gave it a name, and I have never been gladder to encounter a word. A few weeks into the condition, all my pride about high endurance thresholds melted in his consultation chamber, and the tears dropped. I just want it to stop, I told him. The doctor nodded at me kindly, expressed confidence in the treatment. He paused to talk about my distress, about not knowing how he would have fared under a personal experience of the condition, and I was deeply grateful that he stepped outside his doctor-persona for that one sentence of empathy.

Oscillopsia. Finally, the word. Like all Google residents, I read what I could. The descriptions matched what I was experiencing, and there were many posts online of people who said they lived with the condition their entire lives. I braced for the same. I was 43 years old at the time. After many weeks of trying different drugs that only added to my misery, the doctor suggested a drug most commonly prescribed for epilepsy. The oscillations stopped soon after. My relief and gratitude were tremendous.

We had no idea what had caused the oscillopsia in the first place. There was no diagnostic tool for this, said the doctor, but most likely it is an errant nerve in the ear, a vestibular neuritis, an inflammation. A very tiny errant nerve that will not be visible in any scan, even though we went through the MRI to rule out anything else that would show up in the machine. But it is benign, the doctor kept consoling me. Benign. The word was a deep wound in me.

I had no illusions about the drug itself. Just as we did not know the cause, this was not the cure. It was suppressing my symptoms, for which I was grateful, but it was confusing my body. The drug brought about its own challenges, symptoms that made me feel as if my body was not mine, but a stranger's, given to me on hire. The weight my body gained was equally a thickening of mind, a sluggishness that felt like parts of me were being delinked to turn into several floating islands. Like the condition, the side effects of the drug were equally benign, equally isolating. It was the best option, even if dissatisfying, available in that situation, and I had to accept with grace. And three months later, the doctor slowly eased me off the medication, and the oscillations were gone, at least for a couple more months.

One September evening, after a long day of work at an education fair in a distant city, the walls of my hotel room began to rock in that familiar way. The oscillations were back.

A condition between health and sickness

Now that I had a word for the condition, and now that I knew of a drug that could help suppress it, even if it gave the sensation that my body was an alien inhospitable terrain, I began to consider the option of doing nothing. Both the condition and the drug would compromise the guality of my life in different ways, and I was starting to think that I could perhaps just learn to live with the oscillations rather than return to the drug. I braved my way through the days, trying to pace my work, my condition only obvious to the watchful and worried eyes of my partner. I forced myself to read because my work demanded it, but the idea of reading a book for pleasure was out of the question. There were other changes afoot. I was going through a phase when I could not bear to put any more chemical dyes into my hair and decided to be content with being greyer than people older than me. In recent years I had also turned vegan, and with that came reluctance towards anything over-processed with sugar, preservatives and artificial colours. That year, my partner and I had spent ten days in a meditation centre where speech was not allowed so that the mind could flow with one's breath. Perhaps I was primed for a new medical experience, in more ways than one, when a colleague recommended a doctor in the Ayurveda department of our local hospital and I started treatment in January 2018.

I am only too aware that the present narrative is likely to give the impression of the narrator finding a cure for oscillopsia in Ayurveda, the kind of triumphant telling that comes at the end of a long struggle from illness to health. But no, my oscillopsia is very much with me, and the words I type on the computer screen are quivering, so this narrative is *not* about finding a cure in an alternate medical system. Even the notion of cure does not serve me well anymore. To most of us, the absence of the symptom becomes cure, and even a suppressant of the condition (for example, a pain-killer) is akin to a cure when the symptom is unbearable. If seen exclusively from this perspective, my experience of Allopathic medicine and Ayurveda have been identical – I have had several weeks/ months of relief when on the drug/treatment, and the condition has returned when the treatment is withdrawn.

Therefore, and importantly, it is not my intention to make a case for the discipline of Ayurveda as a whole, or to speak in any way of the inadequacies or insufficiencies of modern medicine. I am also highly cognisant of the fact that there are debilitating conditions and sufferings more severe than mine, and that I cannot even speak for the condition of oscillopsia, which is experienced differently by each person.

The effort here is to share a parallel understanding and awareness of health that I have received through Ayurveda, something that has reshaped my conception of a cure. It has forced me to rethink how to negotiate the process of constant close reading and listening to symptoms that becomes almost second nature to the person with a condition, and to extend this to the many daily decisions we take for our wellbeing. More centrally, this narrative is to practice an important principle of Ayurveda, and of Medical Humanities (a discipline that I study) – the belief that the person with any condition is an able chronicler of their body, and the value of their testimony is essential to any medical knowledge that codes or decodes it.

The road of health

The phrase "road to" has been around for too long, and has created a culture of expecting destinations, end results. In common parlance, the road has always been *to* health, the desired end. This was challenged for me in Ayurveda with its insistence on health as process and as something that needs thoughtful recalibrating – to reflect on the environment I live in, the food I put in my body, how I attend to the various ways in which my body speaks.

During my first consultations in Ayurveda, I continued to seek a causality, to know what triggers the oscillopsia, and like most patients who resist being told their condition could be psychosomatic (because that implies I can make this stop, but I can't!), I wanted it to be anatomical, located in a specific nook of my body. Not the ear, said the doctor, but the spine. I had known about my cervical spondylitis for a few years, but it had felt under control, with yoga, and an active pain-free life. The doctor ran his fingers along my spine, till he reached the cross it forms with my shoulder, a concave, then a lump. Under the pressure of his finger, my spine spoke back. Years of reading and writing for long hours, of physical and emotional independence and of hardship, the compulsion to constantly labour - all this I sensed embedded deep in my spine. The doctor continued to read my body, three fingertips (of his right hand) on the nerves of my left wrist. We talked about my digestive system, the diets that could aggravate or ease the condition. The oscillopsia, I would soon learn, lived as much in my stomach, as in my spine. It also lived in my mind, how I perceived its presence, the stress that housed it. The initial lesson and experience of Ayurveda was to move from

description and naming of my condition – oscillopsia (must I really give up a word I had embraced with gratitude?) – to the perception of varied body parts as an interconnected whole. I started to think in terms of whether my body felt light or heavy, calm or agitated, knotted or flaccid, energetic or lethargic, and the many degrees in between.

I was eager to know the doctor's thought process during my treatment, and he explained how Ayurveda might make sense of a chronic condition: Each time our body is exposed to toxins, is fed something that is not good for it, is exposed to trauma, or is compromised in some way, it somehow copes. And it continues to cope for a very long time, giving the illusion of health, till a time comes when the body simply cannot cope or adjust anymore. This is when the accumulated coping of the past turns into morbidity, the pathology surfaces, we have illness and disease. In any treatment, when we accept this disruption, work towards harmony, it teaches us to listen to discordant notes, like mechanics listening to engines or musicians to instruments, and the signals become easier to spot. This perspective helped me get some sense of four decades of my life, the way we push our bodies in youth, the insensitivity we show in our choice of food and drink, the many drugs that trickle into the system, the conditions and people who coagulate strife in us. And all the while, coping, just coping. Just as cure cannot merely be the absence of symptoms, it became apparent to me that health cannot be the invisibility of distress caused to the body. Balance of all the elements that make our body, said the doctor, is Ayurveda's conception of health.

Ayurveda is as taxonomic as any other discipline - it starts with the premise of body types, the balance or imbalance of three doshas (vata, pitha, kapha), the combination of five elements (air, fire, earth, water, ether), and there are specific diets that help in the harmony of these doshas. With its investment in dairy-based formulations, and other animal products, Ayurveda can be a challenge for a vegan, and I had to ask for alternatives several times. Similarly, many of the procedures in *Panchakarma*, or the five actions of healing the body, can be physically demanding. Sometimes there may be a pill or a concoction to swallow, but for the most part, there are several therapies that involve fasting, medicated oils down the throat or nose or ear, forced purgation, enemas, heated oils, exposure to steam, rubbing, coaxing, slathering, immersing. Unlike the commercial spa notion of Ayurveda, these treatments can be unpleasant, and many times one wishes to take flight, because the procedures can be time intensive, often inconvenient to fit into a workday. We persisted, and soon Panchakarma would offer me something completely unexpected.

Following the treatment, far from feeling robust, my body seemed to turn more delicate, not just in various subtle sensations I felt within, but also in reactions towards certain food groups. Foods that were unhealthy for the body but tasty to the tongue organically turned unappetising. Instead, the deep flavours of simpler, healthier foods made every meal much more satisfying. My stomach was thinking, and incredibly, I could hear it! However, the real lesson of Panchakarma was not so much this experiential shift, but the habit of honouring and observing my body, and trusting how I articulate its many vagaries. The Ayurvedic treatment, I then realised, was the beginning of a dynamic sustained coaching regime of management, to train the body (and this includes the mind) to be more sensitive of its own workings. Through the twentieth century's obsession with diet, we had been told that "you are the food you eat". For the first time, I could experience this intensely. Every inappropriate meal was impacting my skin, my spine, my mind. I noticed how the unnatural cold of air-conditioned rooms, long hours at my computer, emotionally fraught moments, tightened my neck muscles and triggered oscillations. I was starting to understand my wellbeing as complex, and constantly recalibrating. I noticed that when the diet is monitored, when I live through my daily activities with mindfulness, when I sleep well, a vital energy pulses in my body, travels in clarity from pore to pore, till a certain steadiness becomes a part of daily living.

About three months into the Ayurveda treatment, the oscillations stopped, initially for several hours, and then for days at a stretch. When the oscillations returned, I felt them to be more contained, in the periphery but not outside the realm of reasonably good heath. Even if this were to be chalked up to a placebo effect, medical science now knows enough not to dismiss these effects, and has learnt that relief from suffering, irrespective of causality, is real and appreciable to the sufferer.

The oscillations come and go, like an intimate friend that only I know, and my future with both condition and treatment remains uncertain. Like most people with chronic conditions, I do not deny that I am weary of it, of the days when I wish the pain running up and down my spine or the objects oscillating around me would stop. But I am aware of the choice I made. Having invited my body, through Ayurveda, to speak aloud and be audible, I must now have the patience to listen.

I try to think of my body as a lantern, the casing as vital as the core, lit from within.

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