

## **The Parkinson's you can't see**

The buzz emanated from my fingertips and I settled into silence, staring down at foggy breaths which obscured the gravel and my mud-splattered shoes. Uptight barks resonated from within, reminding me that I was foreign to this place. I grew anxious as footsteps approached the doorway, not knowing what I would get out of this encounter. The door swung open, and I gazed upon the hunched and skewed figure of M. She was dressed in flamboyant pink and wore a smile that could stave off the biting cold of the winter afternoon, "come on in, I've been expecting you."

We exchanged pleasantries and M escorted me into the living room, shuffling slowly behind. The cosy ambience was a welcome change from that of fluorescent cubicles of linoleum and fabric, which was what I was used to from previous encounters with patients with M's condition. Pieces of mahogany lined the room, reflecting the warm glint of the sunlight. Rows of ornate and dainty handicrafts stood on display within oak frames and transparent trunks. There were photographs of people grinning sprightly, pictures of animals in positions of vivacity, and paintings of scenery and its serenity. It looked like she felt very much at home. With a cautious pirouette, she eased herself into her armchair, and gestured for me to take my place in mine. My furtive glances at her tremulous outstretched hand must have amounted to gawking as she withdrew hastily. Clasp her left hand over her quivering right in a tight embrace, she broke the ice, "what would you like to discuss today?"

The cardinal clinical features of Parkinson's disease are motor in nature<sup>1</sup>. Indeed, patients with Parkinson's disease are often conferred celebrity status in secondary care by flocks of medical students eager to internalise and obtain first-hand experience the telltale signs of the disease. By contrast, non-motor symptoms of Parkinson's disease are less visible, under-recognised and can be debilitating<sup>2</sup>. However, I did not travel down meandering country roads and mud-covered paths to learn something that I could pick up from a textbook through rote learning. I paid a domiciliary visit to M for a separate purpose:

"Parkinson's disease is a very visible disease," I said, feeling slightly ashamed for highlighting her parkinsonism mere minutes into meeting her despite her efforts to conceal it.

"But behind the disease are patients, each with unique stories and needs. Today I want to learn more about the patient behind the disease. I want to learn about you."

M's diagnosis was established not long after her son noticed that she could not hold her camera still. In the midst of recounting her story she decided that it would be easier to show me than to tell me; after all, a picture paints a thousand words. We followed a circuit to visit the portraits dotting the room, bringing faces and figures into focus. She paused at a snapshot of her younger self with an equally majestic equine that she used to ride.

"We were Olympic material. It has been 50 years and, although age was a factor, I wanted it to be *my* decision to stop. I wouldn't have liked to be *made* to give up riding."

Words failed me, but thinking back I realise that the helplessness that I felt might have come from resonance with her overwhelming sense of loss. M's disease had gradually siphoned her ability to ride, write, and photograph, all of which were activities that made her life pleasurable. The vigour with which she spoke against her condition was heart-wrenching yet thought-provoking at the same time. Certainly, her hardship made me feel uneasy, and I was tempted on many occasions to retreat to the safe haven of talking about how her medication helped to fix her problems. However, judging from the smiles that parted her lips and nods of appreciation as she ushered me around, it was evident that talking about her issues was empowering for her, even if I could not offer her a solution.

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Out of empathy for her predicament, I asked M if her circumstances had ever made her feel low. In retrospect, my question seemed to have an obvious rhetorical slant, and inviting her to acknowledge that her disease left her depressed should also have raised her defences. Instead, she became moist around the eyes and her positive front fell, "sometimes I cry and ask, 'why me?' " She disclosed that the mere thought of her future scared her. Part of her fear stemmed from knowing a man who was so advanced in his Parkinson's disease that he was "twisting and wrenching."

"I don't want to be like him, but I know it's only going to get worse. I think I'll be fine as long as it doesn't come too quickly."

I sat in silence, pensively considering the psychological hardship that Parkinson's disease levies on patients who have to face the reality of their disorder. How utterly frightening it felt, even when it was experienced vicariously through empathy. Not really knowing what to say, I expressed my admiration of her efforts to cope; however, this also came with a stinging sensation of guilt. It is never nice to make someone cry, and her fears were wholly valid, but I could not genuinely sympathise with nor allay them. I also felt out of my depth as she shared her perspectives on stem cell therapy and deep brain stimulation. These were topics that she should be discussing with her specialist, but deep down I wondered if this was the first time that a medical professional expressed an interest to understand how she was coping with her disease.

Thinking about the future is ubiquitous in Parkinson's disease patients who have to cope with its progressive and incurable trajectory. Talking about impending events and mortality can be unpleasant and taboo for all involved parties, especially when it involves topics such as dementia, loss of function, and pain<sup>3</sup>. However, it is essential to do so while the patient is cognitively able and verbally expressive<sup>4</sup> as the outcome of these challenging conversations can be of immense value in due course. Reassuring patients that they will be kept physically comfortable allows them

to regain feelings of control. Meanwhile, understanding their priorities to guide intervention down the line ensures that patients' wishes are met to the very end<sup>5</sup>.

At one point, we started to discuss symptoms which were less visible and under-appreciated by the public and healthcare professionals. One of M's "bugbears" which most impacted her quality of life was the combination of abdominal pain and diarrhoea, the latter of which was made significantly worse by levodopa therapy. Comprehensive investigations of her gastrointestinal problems failed to elucidate a cause, pushing M to resort to diet control and careful titration of the beneficial effects of her medication with its propensity to upset her bowels. As she put it, "I couldn't live like this, now all I can have is bland food. Alcohol interacts with my medication and, as a result, I feel like I stand on the side during social events."

Out of sight, out of mind, so the old proverb goes. It is all too easy as clinicians to say that the medication we prescribe is efficacious when it alleviates what we can see. However, M's situation reminded me that the medication used in Parkinson's disease could be a double-edged sword. Less-visible side effects may be debilitating for patients and adversely impact on treatment compliance. It was also plausible that M's bowel dysfunction was a symptom of Parkinson's disease, but she remained convinced that her ongoing "stomach problems" were the result of a laparoscopic cholecystectomy in which the surgeon negligently left a sizable portion of her gallbladder behind. Understanding M's ideas regarding her condition helped me to realise that the systemic symptoms of Parkinson's disease are often inadequately recognised not just by physicians, but by patients alike. While it may be necessary to rule out other forms of pathology in some cases, unaddressed ideas may spur patients to demand extensive and unnecessary investigations, which leads to frustration when test results do not pinpoint the real cause.

Addressing the 'invisible' aspects of Parkinson's disease requires clinical acumen to recognise non-motor symptoms and treatment side-effects. More importantly, we need to invest time to understand the patient behind the disease. Sometimes I feel disheartened that, when I become a

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junior doctor, time pressures will inevitably limit the opportunities to get to know my patients and thereby the care that I envision myself providing. Nevertheless, I am comforted by the fact that the skills that I have been taught and employed with M - active listening, empathy, and collaboration - do not require much time at all. Before we parted ways, M unlocked her clasped hands, cupped my hands in hers, and thanked me. It was unlikely that we would see each other again, but with her moving gesture, she reminded me that I had become a part of her story and she had become a part of mine.

Word Count: 1,500

## **References**

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