

Speaking for Myself

Anatomy of loss: A doctor's perspective

SUPRITA KALRA

All doctors have many patient stories up their proverbial sleeves which they zestfully recount at a drop of their hat but all doctors also have some patients whom we can never forget. These patients are those whom we couldn't help or save. Yet, the doctors, both residents and consultants are hardly ever taught or offered help to handle adverse patient outcomes including mortality.

I had the unfortunate privilege to have been part of the story of one such patient whose family taught me humility and acceptance as they dealt with the finality of loss.

One day, during morning rounds in the Paediatric Intensive Care Unit (PICU), I was told by the residents on duty that a 17-year-old 'child' was admitted with history of seizures at home followed by altered sensorium. As I saw the patient, I thought I recognized the lady with the big child, her calm demeanour and stoic acceptance seemed to bring back memories when she broke my reverie and said, 'madam pahchana Parth ko (madam, did you recognize Parth)' (name changed). I must have first seen him as a 3–4-year-old with refractory seizures when I was a second year resident in Paediatrics. Patients like him still scared me and my batch mates back then because they continued to deteriorate despite our best efforts. Don't worry, his mother had told me, 'last time also his seizures stopped after the third injection'. I looked at her stumped. She had taken her son's disease in her stride and was reassuring me. Sure enough the seizures stopped with the loading dose of phenytoin after having repeated lorazepam twice. The child was quite drowsy afterwards and had to be kept on intravenous fluids and regained full consciousness after 48 hours. After this I saw him multiple times with similar episodes and followed his disease course as his development delay became more and more marked, but with no definitive diagnosis. It could be a metabolic, genetic or neuro-degenerative condition. We discussed the possible differential diagnoses with our consultants in an era when molecular diagnosis was not easily available and understanding of genetic disorders was still evolving. As I passed my MD examination and got posted to a hospital in a faraway state, I lost touch but years later I was posted back to my parent institution after completing my training in Paediatric Nephrology and came

face to face with this patient and his mother whose disease spanned my whole career in Paediatrics.

The child had now grown up physically but not neurologically, bed bound and entirely dependent on caregivers for all his activities of daily living and yet he looked absolutely well kept and cared for. His mother ran me through his decade long journey with finally being diagnosed to have arginase deficiency—a urea cycle defect with hyperammonaemia. Then came their struggle for his special diet, its cost to the family and emotional and physical drain to the whole family. Yet what struck me was the dedication of the family to his care without any complaints or signs of fatigue.

This admission, he had slipped into a hyperammonaemia coma following a brief febrile illness and then deteriorated to have multiorgan dysfunction. The doctors counselled them regarding poor outcomes and sought permission for mechanical ventilation and continuous renal replacement therapy (CRRT) in as non-directive way as possible. However, the family was clear that they wanted to offer him whatever best was possible. So I along with the PICU team went through the motions of ventilation, CRRT and ionotropic support. Our interventions weren't enough to salvage him and he had a cardiac arrest after being on cardio-respiratory support for 48 hours from which he could not be revived.

As we broke the news, the mother told us that the entire family was prepared for the final event since the time we had sought permission for ventilation and CRRT but didn't want to lose out on any chance of his revival. They then proceeded to thank us all and almost consoled the junior residents on duty before signing the final documents. I looked at them in awe and respect. In their loss they had strength to express gratitude and reassure us. I wondered if I had been part of their story to do something for them or they were part of mine to teach me so much love and humility through their loss.

Of course there was no clear answer but I thanked the Almighty for having given me an opportunity to have cared for such a patient and his family and for reminding me that we doctors are just an instrument of His plans.