A MOMENT IN THE LIFE OF A FAMILY PHYSICIAN

A family physician's impossible choices & lessons learned through illness

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MBBS, MMed (FamMed), PhD Department of Primary Care Medicine, Faculty of Medicine Universiti Malaya, Malaysia I was recently diagnosed with bladder cancer and had to undergo four cycles of chemotherapy. After the third cycle, I was scheduled for a follow-up MRI with contrast. The medical officer (MO) conducting the pre-MRI check-up was adamant that I should not have the contrast because my reported eGFR was poor, i.e., below 30 mL/min/1.73 m². I explained that my oncologist and nephrologist had discussed the matter and that they wanted the MRI because my recalculated eGFR was better than the eGFR reported by the lab, and the scans were needed for my upcoming major operation. Following protocol, she checked with her senior, who spoke with me.

The conversation went something like this:

'Prof, the actual reason that it might not be advisable to do the contrast MRI is due to the risk of you getting a condition known as nephrogenic systemic fibrosis that is seen only in patients with advanced renal disease. There is no treatment for this—it is rare, but it can occur.'

'Thank you for telling me this, but I need the scans for my operation.'

'I understand, but you need to know the risk of this condition and decide whether you are able to accept the risk.'

'I really would prefer not to take the risk, but as I understand it, the scans are necessary for my operation. Can you discuss this with my nephrologist?'

After a telephone consultation with the nephrologist, the MO returned to inform me that they would proceed with the MRI because the adverse reaction was very rare.

I was quite affected by this consultation, and now, days later, the encounter is still being replayed in my mind. As a senior consultant in primary care medicine and an advocate for evidence-based medicine (EBM) and shared decision making (SDM), the fact that I could not make my own decision plagues my thoughts.

As a doctor, I must often discuss difficult medical decisions with patients: whether or not to proceed with an eye operation for an orbital fracture in a 90-year-old woman, to decide on end-of-life treatment for a cancer patient, to consider whether or not to start or stop preventive treatment for any patient. I would explain the choices, the pros and the cons, and the evidence—or lack thereof—underlying each decision. Patients would discuss their choices with me, but they would often simply ask: 'What would you do, doctor?'

We give patients impossible choices, just like the choice I faced in my own experience. The two MOs, junior and senior, did the right thing and I am proud that they outlined the risks and considered my choices—but what choice did I have?

I feel that this has been a recurring theme throughout my illness. When I was first diagnosed with lupus nephritis, I was a final year medical student and was told that I had to take high-dose steroids. I knew exactly what side effects I was going to experience. My weight ballooned

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from 70 kg to 120 kg within weeks. It was difficult to speak with patients about their weight problems when I, myself, was morbidly obese. Every day, my face expanded until I thought it would simply burst like an overfilled bubble. Striae blossomed on my armpits, thighs, and abdomen. The night before I took the steroids, I cried and cried—but I still had to take them.

When my bladder cancer was first diagnosed in 1999 (a result of cyclophosphamide therapy), I was devastated and could not speak of the diagnosis to anyone other than my immediate circle of family and friends. In May 2021, I was diagnosed with recurrent invasive bladder cancer, and the diagnosis was still devastating. Medical crises do not get easier to accept with time; one does not get braver or wiser. It still felt as if someone had just punched me in the gut.

At first, I could not tell anyone of my diagnosis-my latest medical crisis. In the first 2 months, I could not do anything. I realised that I lived a lot of my life in my head; my physical body had always given me problems and, to get away from them all, I read books, worked on my medical and research career and, well, lived in defiance of my symptoms and signs. But now I was being pulled back into my corporeal self, and it was difficult. I gave up many things in those first few months: my work, my teaching, my research. It was all I could do to focus on what needed to be done—scans, blood tests, scopes, chemotherapy, and the impending operation.

If I, the EBM advocate, the SDM clinician, the primary care consultant, had difficulty with this, then it must be impossible for patients—or, perhaps a little knowledge is a dangerous thing. Deep down, I know that part of my denial was that I was a preventive medicine doctor; I taught patients a healthy lifestyle, I lived a healthy lifestyle, and I felt ashamed to have renal failure and cancer, the bogeymen of complications that we tell patients they have to avoid.

This has made me realise how much we blame patients for their diagnoses. Perhaps it is because we want to think that we have some control over illness. We can reduce the risks for cancer by not smoking, maintaining the proper weight, doing check-ups, and so on, but, often these things are beyond our control. We can still be that random person for whom the treatment cures or the treatment kills.

What is the moral of the story? As I said, I am not braver nor am I wiser. If I were to speak to the younger me who wanted to do primary care medicine all those decades ago, I would tell her not to think that she can prevent illness or cure everyone, but that she can simply listen and help the patients as much as she can, and offer empathy and kindness. Sometimes that is all that is needed and is more than enough.