

My recent experiences as a patient

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Abstract

As a neurosurgeon, it was a new experience for me to face the consequences of an accidental fall just before I underwent simple spinal surgery for relief from backache. This essay describes how I was affected by the unexpected operations that followed. The physical pain, the anxieties, small inconveniences and the relatively free use of drugs such as antibiotics, that I might have taken for granted in my patients undergoing surgery, now took on a new meaning for me. My perspective on my illness as patient, rather than as physician, and the special care given to me by medical, nursing, and paramedical colleagues were transforming experiences. Based on these occurrences, I offer suggestions on how we can improve our approach to patients.

It may sound ironic that a person who has performed several spinal operations needed to have three himself in rapid succession.

The beginning

Over June and July 2011, I developed pain travelling from the lower back down the left lower limb, with progressive reduction of the distance I could walk without pain. This was against a background of longstanding psoriasis with associated changes in the spinal column. My neurosurgery colleague examined me and decided that surgery was necessary to relieve pressure on a spinal nerve. I had expected such findings. As with any other patient, there was apprehension about the surgery, especially given my age (71 years). I prepared a document listing my advance directives for my colleague and handed it over to him. Briefly, it listed instructions in the event of complications from anaesthesia or surgery that left me severely brain damaged or permanently incapacitated. Such a document is not legally valid in India, but I was confident that he would implement my wishes.

The operation was scheduled for August 29, 2011. My colleague - to whom I had entrusted myself - sought the help of an expert in endoscopic spinal surgery, currently practising in Kolhapur. He kindly agreed to come to Mumbai and perform the operation in our hospital.

Unexpected twist

The next morning before leaving for the operation theatre I went to the toilet and emptied my urinary bladder. While emerging from the toilet, I slipped on the wet floor and fell flat on my back onto the floor. The central segment of the spinal column (dorsal spine) bore the brunt of the impact. As I lay on the floor, in considerable pain, I rapidly checked the movements and sensations of the limbs and found them

unimpaired. This reassured me that there was no damage to the spinal cord or nerves.

On hearing the thud caused by my fall, my wife rushed into the toilet and found me unable to rise because of the pain. She helped me into the upright position and, after the pain had eased a little, on to my bed. The trolley arrived soon thereafter and took me to the theatre.

On reaching there, I informed my doctors about the fall and the pain. Clinical examination suggested injury to the muscles and ligaments. They advised proceeding with the surgery to which I readily consented, as I wanted to be rid of the pain down my left lower limb. The operation went off smoothly and I have experienced no ill consequences from it. The radiating pain appears to have been abolished. I was sent home the day after the operation.

The drugs prescribed were continued at home, paracetamol being taken orally at home in the same dose as was injected in the hospital. As I remained pain-free, on the fifth day I started reducing the dosage with a view to discontinuing it. However, the pain felt after the fall recurred. I raised the dosage of paracetamol, with some reduction but not abolition of the pain. The pain was worse when I lay down on my bed and when rising, and very troublesome even when I turned in bed, awakening me almost every hour or so.

A week after the operation, I was in misery and was readmitted to hospital. Computerised tomographic scan of the spine showed compression of a dorsal vertebra. It was deemed to be such that it would settle over time. A combination of physiotherapy and drugs helped control the pain. I was sent home a few days later.

Using the prescribed tablets I started attending my consulting room in the hospital and could see patients over two hours. Standing and walking were painful, and I stooped visibly when doing so.

As the pain worsened over time, I consulted our orthopaedic surgeon who suggested I see our spinal surgeon. After reviewing the new x-ray and scan films examinations, the surgeon recommended fusion of five vertebrae with the injured bone in the centre. Accordingly I was readmitted and the operation was carried out in two stages, 15 days apart.

Unwelcome side-effects

After each operation, the antibiotics prescribed caused a loss of appetite but this was worse after the last operation. For over 13 days, I was unable to consume food. I could manage three

glasses of fresh fruit juice and water each day, and at best, a small bowl of yoghurt. Eating a spoonful of any solid food made me feel as if I had a huge ball of lead in my stomach. Even after the antibiotics were stopped, this difficulty in eating persisted for over a week.

The consequences were obvious. I lost a lot of weight and there was thinning and weakness of muscles. This was most marked in the muscles moving the hip and knee joints.

I also found myself choking with emotion with abnormal frequency. Gratitude at the unfailing courtesy shown by ward attendants, nurses and doctors; the thoughtfulness of visitors who brought books for me to read; the plight of a friend whose wife was being treated in a room two floors below mine for a serious illness that was eventually to carry her away – and other similar instances – brought me to the verge of tears and I often had to stop in mid-sentence, to avoid embarrassing myself and those around me. This persisted for some weeks, even after I returned home. I am not sure about the cause. I have witnessed it in patients undergoing serious operations, such as on the heart. I wonder whether, in my case, it followed a combination of prolonged pain and sleeplessness before surgery, helplessness in the hospital, the need to rely on others for help in simple tasks such as bathing, passing urine and stools, standing and walking. I was also witness to my wife taking leave from her research for weeks and spending all day by my side, attending to my needs.

When I was sent home on November 20, I was unable to climb or descend a single step. I was taken from my room to my friend's vehicle on a wheelchair and lifted manually on to the seat. On reaching home, I was helped to descend from the car, placed on a chair and carried on the chair to my bed. You can imagine my distress at the extent of my disability. Accustomed to striding effortlessly, climbing several floors and brisk action, I was reduced to a state where I needed help with the simplest movement!

Slow but steady recovery

At home there was slow and steady recovery of sleep and appetite. I continued the exercises prescribed in the hospital and could resume walking with the "walker". It was necessary for someone to be by my side as soon as I attempted to stand, to ensure that I did not fall. My physiotherapist at home assured me that I would improve gradually. This helped my morale.

As I took increasing quantities of food with high protein content and whey supplements, walking improved to the stage where I could discard the walker. This was a defining moment. I had grown dependent on it, fearing a fall without it. One evening a colleague visited me, seeing me sit on my bed, unaided and stand, pronounced that I did not need the walker any more. He asked me to start walking. I asked for the walker. "Why do you need the walker? I am here in case you need support but rest assured you will not need it." Even so, he offered me his hand. Holding it - more for moral than physical support - I was able to walk from my bedroom to the drawing

room with just mild unsteadiness. There he helped me sit and forbade me from using the walker any more. Such was my diffidence that I had to steel myself to do so!

I now walk freely in my home, have progressively become able to climb three floors, walk around the circumference of our terrace and along the nearby sea face.

Fresh x-ray films of the operated area showed satisfactory repair of the broken bone. I should be able to return to work in two months.

How it feels to be a patient

I experienced a progressive loss of morale lying on the bed, being sponged instead of having my own bath and using the bedpan. When absolutely necessary, as in my case, this has to be endured and there was nothing my treating surgeons could do about it. Empathising with me did help, but true relief was only obtained when, at last, I was able to sit, stand and walk.

Like many before me, I bemoan the design and construction of the bedpan, which is especially painful to a person who has recently undergone spinal surgery. Bedpans are usually constructed of stainless steel and are cold, hard and uncomfortable. On the other hand, stainless steel is easy to clean and durable. The use of antiseptics renders them free from germs. Plastic has been shown to form a reservoir for microorganisms. Bedpan liners made of recycled pulp (moulded pulp) or biodegradable plastic, containing absorbent powder to eliminate splashing and spills do decrease infection but are expensive and not generally available in India.

As a member of the hospital staff, I was privileged. All those attending me, from the consultant to the persons helping me with urine and stools, were uniformly kind and courteous.

Many facilities offered to me are not easily available to most patients. I realise this is unfair to them. It is worth bringing this differential care to the notice of young staff members and medical students and helping them devise measures to reduce such differential care for the benefit of those not privileged. As you will see from the following paragraph, it may be practically difficult to treat all patients in the same manner as I was treated.

During the period when I could not take in any nutrition, our senior physiotherapist sent me fresh fruit juice from her home every day. Our dietician willingly offered to make whatever food I desired to my specifications and did so, unfortunately without any improvement in my being able to eat what was prepared so thoughtfully.

The consultants made regular visits and kept me informed of every step taken. I took great care in refraining from any interference in diagnostic tests or drug therapy. I know of the difficulties created when patients or their relations interfere in the treatment. If all consultants were considerate with their patients and explained the need for tests or the form of treatment being administered, this may eliminate interference

by patient or relations, as their anxieties would have been addressed.

I found the resident doctors attending to me in some awe. Their examinations were often restricted to obtaining my opinion of the neurological findings and inspection of the wounds. They were careful to cause minimal pain. On the two occasions during the month I was in hospital for the second and third operations, when I had to request resident doctors to attend to me at night, their responses were swift.

In turn, I took care not to trouble them unless absolutely necessary. This is important as most resident doctors are very hard worked and under tremendous stress. Calls to them at odd hours of the night deprive them of much needed rest. I am fortunate in being a doctor, who can distinguish symptoms that can wait till the next day from those that cannot. Most patients have not been trained as I have been and may be unable to do so. As a result, nurses and doctors may show impatience with patients who make frequent calls on them. The nurses and doctors, in turn, must remain aware that such calls are being made out of distress and need to be dealt with serenely. In many instances, reassurance and good cheer may be all that is needed.

In relation to this, there is another very important point to be made. In many hospitals it is the practice for the resident doctor, when called at night by the nurse, to listen to the nurse's account of the patient's complaint and then prescribe over the telephone without going to the patient's bedside and examining the patient. The dangers of this approach cannot be overstated. The nurse does not have the expertise of the doctor. A symptom may arise from many causes, some of them with the potential to worsen the patient's condition. There is no substitute for examining the patient when called, even though it may turn out that it is for a trifling cause. I did not experience such behaviour during my stay in hospital, but have seen it during my rounds as a surgeon.

An interesting experience was the recording of blood pressure. A nurse would check my blood pressure and tell me that it was 140mm/80mm. Three hours or so later another would check it and find it 170/100 mm. A further three hours or so later, the third nurse would tell me it was 100/70. Such erratic readings can puzzle the clinician and even prompt prescription of a drug to lower blood pressure when it is not really needed.

Some suggestions

- Bathrooms and toilets, especially in hospitals and clinics, must have tiles with surfaces that are not smooth and reduce the chances of slipping and falling. The ill are especially prone to such injuries. It is also necessary to provide firmly anchored bars along the full lengths of the walls of toilets and bathrooms that can be used by patients to support themselves.

- The blood pressure instruments may need calibration. I also wonder if there should be periodic exercises when the blood pressure is recorded by different nurses, one after another, on the same person to check on consistency in results. With the urge to treat any finding deemed abnormal, this is essential to avoid unnecessary therapy that might even cause complications.
- A small rise in temperature – to 99.8 degrees – prompted our medical consultant to request white cell counts and when these showed a rise in total count from 90,00 to 11,000, to change antibiotics. At that time, there was painful swelling of a vein at the site of infusions. This was not considered as the cause for fever and mild increase in white cell count. I wonder whether it would have been in order to watch the temperature over the next day or two and obtain another white cell count before changing antibiotics.
- My complaints of loss of appetite usually inspired comments such as: "Consider food as medicine and take it slowly." "Take small quantities every hour or so." I had already tried these measures but the feeling of a huge load in the stomach rendered these ineffective. As a consultant later told me, many patients complain of loss of appetite on such antibiotics and we may need to take such complaints seriously. Often – especially when the patient is a lay person – several complaints are brushed aside with a statement such as "Don't worry about this. It will soon disappear." Spending a little time explaining the basis for the unwelcome side-effect, instituting measures to ameliorate the symptom(s) when possible and altering the principal therapy when the side-effect from it is causing damage will go a long way towards helping the patient.
- Suggestion boxes are usually maintained at central locations in hospitals, often on each floor. It is sad that most patients disregard them and do not voice their own observations of shortcomings and recommendations for improving the care of patients. Hospital authorities may also be at fault, as other priorities or problems make them neglect these important feed-back messages born of practical experiences.

Looking back

In summing up, I am, surprisingly, not unhappy at having undergone this experience. It has enriched me in many ways, most of all by emphasising to me the vast stores of affection and care available to me. These were lavished on me by my colleagues in hospital, my wife, my children, other relatives and friends. I am deeply humbled.

As a consequence of the severe loss of appetite during the last fortnight or so in the hospital, I have become lean – a welcome development – though I would not recommend this as a means for losing weight!