

Kashi's Story - Karnataka, India

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I had just returned after a three-day vacation utilizing the rare extended weekend holidays. Having successfully manouvered the heavy morning traffic of Bangalore, I was walking into my consulting room, preoccupied with the different messages from my team, when I noticed from the corner of my eye a middle aged gentleman in the lobby, eagerly yet timidly trying to get my attention. I was all set mentally to begin another week of our work, but twenty-five patients were already waiting in our oncology wards for palliative care consultation. To maintain efficiency, I decided to proceed with the ward rounds before getting locked in with office consultations. Somehow, I successfully managed to avoid making eye-to-eye contact with the man in the lobby.

Minutes later, climbing up the steps to the ward to begin my rounds, I noticed that Lohith, my ever pleasant nurse, was looking perturbed and was glancing back towards the same gentleman in the lobby, who was following the movement of our team with his pleading eyes. I stopped and asked Lohith what was going on.

The old man was Ramaiah, father of the 21 year old Kashi who had presented to our palliative care clinic at our cancer care centre few weeks ago, with diagnosis of advanced colon cancer after having exhaustive disease modifying interventions. I clearly remembered the distress of the young man who came to us with excruciating pain and breathlessness. We had titrated opioids and had controlled his symptoms with a total daily dose of 100 mgs of oral Morphine and few other medicines. I also remembered his cheerful demeanor during discharge, as he shared stories of his two naughty cows, Devaki and Leela and how he managed their tantrums. He was happy and looked forward to returning back to his dear village and his friends.

Why was Ramaiah here? The distress in his eyes clearly conveyed that something was very wrong. What had happened to Kashi?

I was concerned! I cut short my rounds and returned to the clinic. Ramaiah had tears in his eyes as he entered my office.

He was here to collect the same medicines that gave so much comfort to his son. He had arrived one morning, unaware of the fact that our out patient clinic would be closed on the Republic day of India. Unable to procure the medicines for which he had travelled by train for 22 hours and with very little money to spare, Ramaiah had to sleep that night on the street near the hospital. Ramaiah broke down sobbing as he related how he had come over eagerly in the morning to collect the medicine and how important it was for him to return home quickly and provide some relief to his son, who was inconsolable and groaning with agonizing pain.

But...I needed to know something else...surely, I had referred him to a hospital few hours from his village which was stocking opioids. Why did he travel so far to Bangalore?

Ramaiah had gone to the hospital nearer to his village, but the centre was no longer stocking the narcotics.

Sensing the seriousness of the situation I arranged for him to get the medicines immediately. We also made alternative arrangements for reaching the medicines from our hospital at Kashi's home, at regular intervals. His reviews continued through telephonic interviews and intermittent reporting by the relatives.

Later, I found out that the concerned hospital administration, near to Kashi's village, chose to discontinue stocking narcotic medicines as they had neither the human resources nor the legal capacity to engage with the bureaucratic agencies. The legal permit consisted of five licenses, each with expiry periods of a few months, which were required to be renewed and maintained for legal stocking of narcotic medicines. The punishment for errors in stocking or accounting were harsh, even up to 10 years of imprisonment. The easiest option for the hospital was to discontinue stocking. This was also the story of most hospitals in Karnataka and in many other states of India after the Narcotics Drugs and Psychotropic Substances Act [NDPS Act] became the law of the country in 1985.

The irony of the situation was that the international treaties to which India was a signatory, firmly stated that opioids are essential medicines and should be available for the needy without any hindrances.

I began working on changing the situation first in our centre in Bangalore, where access to opioid medicines 'out of hours' needed much improvement. The experience with Kashi's family also changed my narrow perspective of just being involved with clinical interventions of those patients who manage to reach us for palliative care inputs. I realized that there is no one else other than us, healthcare professionals, who would talk and bring awareness to policy makers and other stakeholders. I gradually became more actively involved with advocating reorientation of narcotic policy language and implementation strategies towards easier stocking of opioids at institutions and to make pain relief accessible to the patient population of India.

Kashis of our country or anywhere in the world should not suffer so. It is their right to have access to essential medicines for pain and symptom relief when and where they need it. The needless suffering from excruciating pain should end!