

Short Communication

Kids with Cancer

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Gender discrimination is practiced in a number of countries including mine – where to be born as a girl is a curse. The programming of men is such that they rarely recognize gender discrimination. In the past, I too have overlooked it and often ignored it, but my recent close encounter with this malaise shook me. My visit to Delhi was to make a film on shortage of morphine for cancer patients in India. During my short stay there, I met other colleagues who were fighting for the same cause. To bring this into the public domain, TV crew of a channel and I visited an organization devoted to the welfare of children with cancer. The TV coverage was to be on the pediatric patients of cancer and the center that cared for them.

The facility is in a down market, multi-storied building in South Delhi. A large room with curtained off beds serves as the in-patient ward. The adjoining room is a small TV cum recreation room. When we reached around 2.00 pm, most of the kids were in the recreation room. The TV crew asked me to sit and chat with the kids. I pulled up a stool and sat near a 15-16 year old boy. His head was clean shaven, and he had a plaster on his left leg. The boy gave me a wide smile in welcome. I made myself comfortable; I smiled back and began.

'Hi, I am Ravi. What is your name?'

'Nadeem*' he said.

'What did you do to your leg?'

'Hurt it, while playing.'

'Football?' I queried further.

'No' he said 'Cricket'

'What do you like best, batting or bowling?'

'Both, I like batting and bowling'

'What about fielding? Nobody ever likes it, right?'

His answer was a big bright smile.

During this exchange, a few boys and girls dragged some stools for themselves and joined us. I began by asking each one their names, and pat came the answers.

'Neha*' said a doll like girl.

'Abdul*' said another child.

'Sheela*' said another skin head whom I would have sworn was a boy.

'What do you like to play?' I asked, and again. The answers came fast and furious.

'Skipping'

'Marbles'

'Hide and seek'

'Nothing' said Abdul.

I turned to him and asked 'Nothing? Surely Abdul* you like some game?'

'I can't play' he said, showing me the stump of his amputated leg. Nothing below the knee. It was not that I had not seen his leg; I just wanted to behave normally with him. I had ignored the stump, to treat him like any other child. Thrown off balance, I wondered what to say, but the solution came to me very quickly.

'You can play carom' since I had seen a carom board when I entered the room, this comment immediately caused a stir among the kids.

'We've got a board.'

'Nadeem is the champion.'

'No, Neha is, she always wins.'

'No Nadeem is, he beat everyone last time.'

Nadeem seemed popular and the eldest of the lot too. Fair and delicate in constitution, everyone looked up to him. I was surprised

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to see them giving credit to one another as the champion. While the carom board was being set up, a feeble voice called out.

'I too want to play.'

The voice was of that of an 8 year old girl, lying on a stretcher by the wall. Something disturbed me about her. She had a football sized growth on her right thigh. The skin over the growth was taut, and her face pained. The whole group fell silent. Probably like me, they too were wondering how to get the little girl participate in a game which required sitting up on a chair or a stool.

'That is Shanta*, she came in this morning' Neha informed me.

I went up to Shanta 'Do you want to play?'

'Yes' was the reply.

'Can you sit in a stool?'

'No' she said.

'Would you then like to watch the TV?'

'Yes' she said.

The TV was switched on, and shortly the children were riveted to it. We made our way to the office for some food, ordered from a nearby eatery. The conference table had been converted to a dining table. The food was laid out. I stared at the food, unable to start.

'Come on. Start now' said someone.

I continued to stare at my plate full of *Rajma* and *Chawal* (Kidney bean curry and Rice), unable to start. For a few moments I was lost, everyone watched me and waited.

'What is wrong with Shanta?'

'Osteosarcoma'

'Untreated?' I asked.

'Shanta, was six years old when she was detected to have osteosarcoma by a local Doctor near Rohtak. She was referred to Delhi for treatment. After 6 months her father brought her to All India (All India Institute of Medical Sciences). I saw her there first. Immediate amputation above the knee was advised. Her parents did not agree.'

'They should have come immediately after she was diagnosed, and a six month delay can sometimes make the treatable, untreatable. None the less an amputation could have saved her life. Why was it not done?' I asked.

'The parents were not in favor of it; after all she is a girl.'

'How does that change the treatment or the outcome?'

'It doesn't change anything. The parents did not want to amputate her; because they knew that none in their village or neighboring villages will marry an amputee.'

'But this girl is a kid. Where does the question of her marriage

come?'

'If possible, they would have married her off, and then it would hopefully be the problem of her in-laws. In any case, amputation of girl is unheard of, since nobody wants an amputee around, least a female amputee.'

'You mean they did not amputate knowing full well that if left alone the cancer may kill her, and kill her fast?' I was shocked.

'That's it, you now understand it. Do you know that they did not bring her to Delhi for the last one year, for treatment? Now she is in the terminal stage. I forced her mother to bring her here for palliative therapy. Her grandmother said – what is the point of spending money for her medication, now that she is going to die.'

'Good God! How could she even think of such a thing?'

'Not only did she think, she said it aloud a number of times, right in front of Shanta.'

'What?' I was too shaken up to think straight.

'It is curse to have cancer in this country, and in many parts, it is a curse to be a girl. But to be a girl with cancer is probably the worst fate one could ever suffer.' The nurse remarked.

I just left the table. I just couldn't eat. Haunting me was the fact that just one floor above me there was a little girl in unimaginable mental and physical agony. After pottering around for some time I went back to the kids TV cum recreation room.

Some kids had gone to bed, some were still playing carom. Shanta was no longer on the stretcher, but she lay on a couch. She was watching a TV program, but her eyes were heavy with sleep.

'She has received her first dose of morphine and is pain free, for the first time in months. The relief has probably made her sleepy.' The nurse told me that she will be shifted to the first bed that becomes available. Shanta smiled at me when she saw me, she beckoned me closer and whispered

'Uncle I want to live and get well. You will help me, won't you?'

I am not an oncologist, I am not even a palliative care specialist, I happened to stray in this field by an accident of fate. My visit to Delhi was to help easy access to morphine for patients in need of opioid analgesics. But Shanta knew nothing of this, for her any adult who visited her was a doctor.

'Don't you worry' I said 'leave it to us, we will make you well'.

Palliative care experts believe that we should no give false hopes to patients. Someone well trained in this field may find fault with my response. Having spent very little time in palliative care, I have not learned many of their methods. But I have become an accomplished liar. Only Shanta can tell you if I was a convincing liar.

*All names have been changed to protect their identities.