

CASE STUDY

A terminally ill child in a public hospital

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As a college student, I would spend 10 to 15 hours a week in public hospitals, escorting patients and working on social service projects with medical students, interns and residents.

Today, as the head of a school for slum children, I am called upon to intervene when my health workers have failed to resolve issues. Recently, a 14-year-old girl from our school was hospitalised with a diagnosis of tuberculosis. I first heard of it when the parents came asking for help to prevent the hospital (a teaching hospital in Mumbai) from forcibly discharging her. The child's teacher went to the hospital and asked the social worker to intercede. She ensured that the child was not discharged.

The next day I was called to the hospital urgently because the parents wanted to shift the child to a private hospital. As far they could tell, the doctors had withdrawn all treatment. On arriving at the hospital, I went through the child's medical records and it was clear that the child was terminally ill, the TB having spread to the lungs and the brain. She was comatose. I listened to the parents' complaints. They felt that the treatment was being withdrawn because they had refused to take their daughter home; they were being punished for that refusal. Nothing in their manner or speech indicated that they had realised that their child was beyond help. Instead they kept telling me that the doctors insisted that their child would take a "long time to recover" so they should not occupy a bed.

We searched for the resident in charge of the unit, but could not find her. The father did not know any doctor in the unit or department other than the resident. So I accompanied the father to the outpatient department in order to meet the lecturer whose name was on the medical record. She knew about the case and said that the child had a very poor prognosis. However, she was quite clear that the child should not be discharged. I told her that I was trying to dissuade the parents from shifting the child to another hospital and she agreed with me.

I then called the father's brother and sat with both men and explained to them the situation as best as I could. It was clear

from the father's reaction that this was the first time someone had explained to him that his child was likely to die. He first reacted with shock but then was relieved that he now knew the truth. In fact they insisted on buying me coffee before I left.

That night the father called up agitated, complaining that his daughter had been shifted to a corner of the ward where there were only seriously ill patients. Specifically, he added, "HIV patients". I told him that this did not put his daughter at any risk but this was only part of his worry. This section of the ward was stinking and unclean, he said. He could not bear to be there. I did not know how to tell him that his daughter had probably been triaged out. All I could suggest was that he go back to the lecturer we had spoken to in the morning. He hung up in disappointment. I did not hear again from him. My teachers later informed me that the child spent another two weeks in the hospital before dying there.

I do not want to pass any judgment on anyone because I don't know the other side of the story. But there are some things I just cannot understand. Why were the parents unaware of the seriousness of their child's illness? Were they not told? Or is it that they were told but could not understand? True, it was easier for me because I know the family and as a social worker I am trained in counselling. But it was not my job; the attending doctor should have told the parents the truth.

Second, why was the resident so desperate to discharge the patient when the ward was clearly not full? From the records I could see that the necessary treatment was being given. But the behaviour of the staff had convinced the parents that their child was being neglected; she was being punished for their actions. If I had not intervened I am certain that they would have tried to shift her to a private hospital. The result would have been a burden of debt from which I wanted to protect the family.

But I wonder what my efforts produced. For the parents, their grief may only have been compounded by humiliation and frustration.