



Manoranjitham and her father – a heart-rending palliative care story

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About twenty-five years ago, I (Rajkumar Cheluvappa, the first author) was a young intern completing my medical degree in the state of Tamil Nadu, India. I was doing my compulsory clinical rotations, also called internship at a large government hospital. During one internship posting, I was assigned to an open-bedded ward with around forty beds in the room without an iota of privacy between patient beds. One of my patients was an eight-year-old girl named Manoranjitham.

Manoranjitham had a congenital heart disease, presenting with an acute exacerbation of her persistent clinical manifestations of cardiac failure. She had severely compromised lung function and cyanosis, both central and peripheral. Manoranjitham had already been examined by several multidisciplinary teams over the past couple of years and deemed unsuitable for corrective cardiac surgery as Manoranjitham had well-established Eisenmenger syndrome, with pulmonary hypertension and reversal of cardiac shunt (1). While treated for some of her symptoms, the specialist doctors ruled out restorative surgery as a management option due to the complexity of Manoranjitham's case and the terminal nature of her condition. Manoranjitham's father, who cared for her a lot, initially did not understand the depth of the situation and seriousness of her clinical condition. Therefore, I had to explain to him almost every day that Manoranjitham's condition had a bad prognosis, and she did not have long to live.

However, over a couple of weeks I was posted in the ward where Manoranjitham was admitted, I found myself becoming more and more emotionally attached to Manoranjitham and her father. I would tell her stories

and sing songs to her, and she would always respond happily. Both loved my jokes. It was a good case-study in transference and countertransference (2). Manoranjitham's father used to narrate aspects of their life, including lurid and sensitive details which are best left out of this narrative. Suffice to say, Manoranjitham's family members were labourers eking out a pitiful existence. The family lived in the rural hinterland servicing the local urban area.

The hospital ward where Manoranjitham was admitted did not have inbuilt security features or security personnel guarding it. The medication cupboards were mostly unlocked and often understocked. Along with other interns, I would frequently take antibiotics and other medication vials and cache it away in different parts of the ward. This was the only way to prevent thievery and wastage, whilst ensuring our allocated patients would get their medications on time. Manoranjitham and her father became experts at identifying the medications when stocked. They cautiously waited and watched for the time the medication cupboards were stocked and picked out the correct medications required for my allocated patients including Manoranjitham. When I visited the ward to do my assessment and medication administration, Manoranjitham was ready with the medications I needed. As I often said, we "had a good working relationship"!

Manoranjitham was on antibiotics, diuretics, and a host of other medications as I watched her deteriorate, improve, and deteriorate again. She was given only a few months to live, and although palliative care was in its infancy and not well-established in India, she was officially classified to be in the "palliative category" (3). However, Manoranjitham's father did not want me or the medical team members to

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explicitly state that to her. Nevertheless, Manoranjitham seemed to understand more about the reality of her situation as the days went by. The direction of her illness trajectory and the hushed discussion tones that her father had with the medical team members obviously make the prognosis clear to her. Eventually, Manoranjitham explicitly acknowledged that she did not have long to live, although it was unclear what that actually meant to her tender heart and mind.

Although Manoranjitham's health waxed and waned, it was officially decided that she was to be discharged with a set of medications and home-based palliative care guidelines. At this timepoint, Manoranjitham had become substantially weaker than how she was when she was first admitted in this ward. Manoranjitham's father was told to expect her to pass away in a few months. I was in the ward when Manoranjitham and her father left the ward. Manoranjitham was heartbroken, not only because of her health, but also because she had to leave me after the strong transference-countertransference bond that the three of us had developed with each other (2). Her father was holding her as she was too weak to walk. She writhed in his arms several times stretching out her arms and forearms to reach out to me. She took hold of my arms and would not let me go. She dug her blue, clubbed fingernails into my skin and subcutis. She was crying bitterly, and started to wail, stating she did not want to leave me and go. I was in tears myself. However, her grip was weak, and I could break away easily. She tried to reach out and grab me a couple of times more. However, her father separated us and carried her away. All three of us were in tears as she left the hospital and the city for good.

I never witnessed such an intricate and selfless bond between a father and daughter. I saw a poor father who carried his sick daughter to the ends of the earth and back. I saw an affectionate and dedicated father who took the main role in caring for his daughter. I saw a simple, but optimistic father who hoped and tried hard to find a cure for his daughter's ailments. I also saw a father give up fighting and give in to the inevitable when he realised the futility of seeking further treatment. My experience with Manoranjitham and her father inspired and strengthened the bond I currently have with my children. It also spurred my interest in human pathophysiology and research. The time I spent with Manoranjitham, and her father left an indelible impression on me, my priorities, and my career path.

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Footnote

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