

Modern Marvels of Children's Palliative Care

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Opinion

RR Pravin, a Singaporean medical student, shares his reflections on patients he encountered during his paediatric complex care elective at the Montréal Children's Hospital

Children's Palliative Care has no limits. With the advances in medical technology, children who are diagnosed with life-limiting or life-threatening illnesses have an increased quantity and quality of life. Here are 2 stories of how I believe children's palliative care has changed not only medicine but the lives of children and their families as well.

Working as a student intern at the Montréal Children's Hospital (MCH) during my elective, I had the opportunity to interact with families who had children with rare and complex conditions. One day, I was following my consultant to see another patient when a mother stopped me along the corridor. Her daughter had Trisomy 18 and was 8 years old. I stopped in my tracks in disbelief because what she had said did not correspond with my medical knowledge. I knew that Trisomy 13 and 18 were not exactly compatible with life. I looked at her in awe and curiously peeked at the girl in her pram, waving to her as I usually do.

'Son, your textbooks are a lie. All the doctors told me that she was not going to make it and asked me to terminate my pregnancy. I said if she was alive in my stomach, she could very well be alive out of my stomach. I kept her. Look at her, she defied medicine,' the little girl's mother said, almost reading my mind. I was pleasantly surprised. When I examined her, she had a huge, unrepaired ventricular sepal defect and significant scoliosis. I knew that surgery could not be done for her as the risks of general anaesthesia would far outweigh the benefits. Nonetheless, the girl was smiling at me the entire time, not wincing when I turned her over to examine her.

'She likes you – normally she cries when they try to examine her,' her mother added. I was rejoicing inside but at the same time, I was amazed by the resilience of this mother and her daughter. An 8-year-old Trisomy 18 must be one in a million. She was thriving and developing relatively well for a kid with Trisomy 18. For some reason,

I felt glad that her mother made the right decision when she was first antenatally diagnosed. Here was a beautiful life that was almost terminated but with the support of the Paediatric Complex Care and Palliative Care services, I was reassured that this girl will have a great quality of life.

The pleasant surprises continued during my 2 month elective with MCH. It was a Friday afternoon when the next patient arrived. She was an unscheduled, acute visit and the doctor on service told me that she was an extremely special child. Having seen so many miracle kids, I wondered what more could I see.

The girl arrived, sprawled on a special chair with an oxygen tank and a tracheostomy. She had been declared brain-dead but her parents had insisted on keeping her alive, acknowledging that there was life within her. Her parents had argued with ethics boards and gone against many medical opinions to keep her alive. It was a difficult moment for me because I thought it must be difficult to be trapped in a body without much life in it. However, she was comfortable and not in pain. She was saturating well.

What struck me most was her parents' determination to keep on fighting for her to be alive. Many years ago, this would not have been possible but with concrete complex care and palliative care programmes in place for the medical care and welfare of such children, their dreams have become a reality. I told her parents in French, 'You're doing a fantastic job. I have never seen anyone who loves their child as much as the both of you'.

With the development of medicine, children with complex conditions will be living longer. However, besides adding years to their life – it is equally important to add life to their years and that's why Children's Palliative Care is the future of Paediatric medicine.

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