Special Article

MAPPAC Malaysian Association of Paediatric Palliative Care

Issue No 33
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Palliative Care is More Than Just End-of-Life Care

A reader once reached out to me via Facebook, saying she could understand the challenges I face every day with the children and families in need of palliative care. This is because she, too, is the mother and long-term caregiver of a child with cerebral palsy. She expressed her gratitude for our efforts to help these children, allowing them to experience peaceful days.

When I asked if her child had received such services, her response was, "Well, my child isn't at the end-of-life stage yet, so I don't think we need palliative care services."

Another instance involved a colleague whose mother suffered from severe dementia, ultimately losing the ability to care for herself. Being bedridden caused painful bedsores, making it hard for her to sleep. When he contacted me to consult about pain relief options, I suggested he could reach out to a home hospice team. After a moment's hesitation, he replied, "My family and I can manage. I just need time to accept it." He eventually had to face many care-giving issues on his own until his mother's passing.

In our hospital palliative care team, our primary focus is on helping children and their families continue to live well. End-of-life care makes up only about a tenth of our work. Often, as soon as a child is diagnosed with an incurable disease, we step in to support and care for the family. These diagnoses may include cancer, cerebral palsy, congenital heart defects, kidney failure, muscular dystrophy, among others, with these children often living months or even years.

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During these times, how can we help them live well?

First, we control pain and other distressing symptoms through professional use of medications and non-medication approaches to ensure the child's physical comfort. We also engage the child and family in warm conversations to build a mutual understanding of care goals (through an Advanced Care Plan, or ACP). We further assist the child in expressing their thoughts and feelings to fulfill their wishes and dreams. Supporting caregivers is a crucial part of palliative care, including providing accurate knowledge about the illness, symptom management, medication usage, care skills training, regular care assessments, emotional support, rest opportunities, and helping them establish family and community support networks.

In 2018, a team providing home-based pediatric palliative care in Singapore published a journal article on the impact of their service over the previous three years. Their findings showed that, compared to children who did not receive palliative care, those who did had two fewer hospital admissions, were able to stay at home for 52 additional days in the last year of life, had five times more opportunities for ACP discussions, and saw a reduction in medical expenses by up to 87%. As a result, the quality of life for children and families improved significantly in the first year of care.

Early access to palliative care not only helps children spend their final days in comfort but also creates more beautiful moments in life for them and their families.

Article featured is by our regular contributer **Dr Lee Chee Chan,** President of MAPPAC. His articles are also featured in various media and publications. We look forward to having more articles from him to be better informed on paediatric palliative care.