

By Dr Michelle Tay

Pain, Pain Go Away



“She was not in pain it was very peaceful. We even went to McDonald’s yesterday because she wanted to have her favourite ‘Big Breakfast’. I wanted to pack it back for her but she wanted to go there herself. Thank you so much doctor ”

Those were the words that greeted me as I paid my condolences to Mrs X at her daughter’s funeral. Mrs X was actually smiling a little as she recalled the last moments of her daughter’s life.

Sharon (not her real name) was two when she was diagnosed with bilateral retinoblastoma. There were brain metastases upon diagnosis. Her parents consented to bilateral enucleation of her eyes but defaulted after the first dose of chemotherapy. She was lost to follow-up until one year later when she was admitted to KK Hospital (KKH) with lethargy, vomiting and thigh pain. A day after admission, a referral was made to the pain management team.

Mr and Mrs X expressed their wish as well as Sharon’s, for her to spend her remaining days at home. They preferred the home environment to that of the hospital. After a lengthy discussion with the family to prepare them for what laid ahead regarding progression of symptoms and their management, they were introduced to the

palliative care arm of the CMF-KKH Pain and Palliative Care Programme. Sharon’s pain was controlled and she was having fair oral intake when she was discharged 2 days later.

It was not smooth sailing for Sharon; she had to be admitted once for blood transfusion and a second time for pain control. It took almost two weeks of daily home visits by the palliative care team (they had to visit her two to three times a day on many occasions) before we managed to get Sharon to be comfortable. As she deteriorated, modes of analgesia had to be adjusted. She was switched from oral analgesics to subcutaneous morphine; but she started to bleed from thrombocytopenia and was finally started on fentanyl patches.

Although Mr and Mrs X were educated and informed young parents, they had reservations about opioids. This was so even though I had specifically “educated” them on the first occasion we met (Sharon did not need opioids at that stage). After several sessions, they were

Dr Michelle Tay is a Consultant at Department of Paediatric Anaesthesia, KK Hospital. She is always aspiring to be a loving and supportive wife, a caring and understanding mother, and last but not least, a reliever of pain and suffering.

finally convinced of the benefits of adequate pain relief and not as apprehensive of the “side-effects” of opioids.

Sharon was under the care of the palliative care team for two months before she passed on. During that time, we had to manage the family as well. For a family that was prepared to have a child die at home, there were still many psychological emotional issues that had to be addressed. Mr X was trying to cope by putting up a brave front and working very hard (typical of many men’s reactions to losing a loved one). Two weeks before Sharon’s death, we sat down with Mr X and managed to get him to open up. He had a good cry and also took our advice to take leave from work to spend time with Sharon before it was too late. Sharon’s oldest sister (aged 8) was so upset at the sight of Sharon (she was rather pale and lumpy mets were popping up rapidly on her skull, jaws and abdomen) that she refused to enter her room. She also had a hard time excepting Sharon’s imminent death. A child psychologist visited the family and had several sessions with Sharon’s siblings.

This story is typical of palliative patients on the NKF CMF-KKH Pain and Palliative Care Programme, which was set up in March 2005, in collaboration with National Kidney Foundation’s (NKF) Children’s Medical Fund (CMF). There are two arms to the programme: Pain Management and Palliative Care.

PAIN MANAGEMENT

We have a multidisciplinary pain team to manage pain in children – the first in Singapore. We manage both cancer pain and non-malignant chronic pain in children. As pain management is an integral part of palliative management, I will now elaborate on non-malignant chronic pain. Most of the patients we see in the pain clinic have one or more of the following: chronic headaches, recurrent abdominal pain (RAP), non-specific musculoskeletal pain, neuropathic pain or pain resulting from disease or injury.

A recent German survey of 715 children aged 10 to 18 years found 610 (85.3%) of them to have experienced pain in the preceding three months; common complaints were headache 65.6%, abdominal pain 47.7%, limb pain 46.4% and back pain 38.6% (Roth-Isigkeit 2004). The prevalence of headache is reported to be 20% in preschoolers, increasing to 50% at 9 years and 70% in adolescents; recurrent abdominal pain is found to be present in between 10.8% and 36% of children, and 40% of children have back pain (Antilla 1996, Aromaa 1998, Antilla 2002,

Rasmussen 1991, Apley 1958, Faul & Nicol 1986, Oster 1972, Berg-Kelley 1988, Larson 1991).

Most of these figures are from Europe. There is very little epidemiological data on paediatric chronic pain in Asia. A Malaysian paper reported RAP in 11 to 16-year-olds to be 10.4%, while a recent local paper found a higher prevalence of 23.4% (Oh, 2004). Unmanaged chronic pain results in functional limitation, school absentism, sleep disturbance, inability to perform sports, impaired relationships and social activities, depression and high healthcare costs. As many as 20% of children with chronic pain have had to repeat a school year (either part of or entire year); and 30% of patients seen at a particular pain clinic had one to two visits per month to medical professionals in the 12 months prior to being seen at the pain clinic (Jones 2004).

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As chronic pain in children has multiple causes (often psychosocial factors play a major role) and affects the entire family, an integrated multidisciplinary approach is ideal and mandatory. The multidisciplinary team comprises the pain specialist, psychologist, psychiatrist, physiotherapist, occupational therapist, social worker and play therapist. Patients will undergo a thorough physical examination, appropriate diagnostic tests, and evaluation of contributing situational factors. Medications, physical therapies, and cognitive-

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behavioural therapies will be incorporated into a flexible, child-centred programme. Multidisciplinary teams are required to identify the specific causes and to select the best available treatments. The reported outcomes of such a multidisciplinary pain clinic in Melbourne Australia have been good: 23 out of 29 patients who had missed more than 40 days of school because of pain attended school regularly once treatment for their pain syndrome commenced; 70 out of 76 children who missed between 5 to 40 days of school attended school regularly after intervention; 88% regained ability to participate in sports (129 out of 147); and sleep disturbance was successfully managed in 88% (129 out of 146) (Chalkiadis 2001).



Dr Michelle Tay with family.

PALLIATIVE CARE

Likewise, this programme is also the first palliative service in Singapore that is dedicated to the care of terminally-ill children or those with life-threatening conditions. These include oncology patients, children with chronic neurological conditions or those with inoperable cardiac conditions. The Palliative Care arm of the programme concentrates on symptom management (particularly pain relief), comfort care and psychological support for these children who prefer to spend their remaining time in the comfort of their homes and presence of loved ones, rather than in the hospital.

Nurses from KKH will visit these patients

at home to ensure they are pain-free and symptom-free, as well as to provide guidance and support for parents and family. When needed, members of the multidisciplinary team will also visit the children. Basic equipment such as oxygen concentrators, wheelchairs, syringe-drivers or PCA pumps for morphine (free-of-charge), and medication will be provided as well as support for care-givers and family members. As with any palliative programme, a lot of effort and time is normally spent on educating patients and parents regarding opioids usage in order to dispel morphine myths that are rampant beyond imagination. Family members are also supported through bereavement, weeks after the child's death.

Studies worldwide have shown that 50% to 66% of children with terminal diseases die in hospitals despite their wishes to remain at home. It is hoped that with the NKF CMF-KKH Pain and Palliative Care Programme, we can help these children fulfill their wish to be with their loved ones in the comfort of their homes.

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I remember remarking to my husband that I have never seen a coffin as small as Sharon's. I suppose I will get to see more as the Pain and Palliative Care Programme expands. It remains my only wish that every parent will greet me with similar words: “He/She was not in pain it was very peaceful.” That is the ultimate reward a pain specialist can ask for. ■