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Case Report

PALLIATIVE CARE FOR A CHILD: ROLE OF A PRIMARY CARE DOCTOR

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ABSTRACT

A 7-year-old boy with a diagnosis of advanced medulloblastoma refractory to treatment was discharged from hospital for further palliative care at home. During this short and eventful period, the child developed spinal cord compression with progressive weakness of upper and lower limbs, neck pain, faecal and urinary incontinence. This case highlights the important roles of a primary care doctor in the provision of palliative care for a child in the community.

Keywords: Palliative care, paediatric, primary health care.

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BACKGROUND

Palliative care for children is an area that is still relatively new in Malaysia. There is a great need for good care to provide the best possible quality of life in the final moments of a child's life. Symptom management for a child requires a bio-psychosocial approach to caring that has to take into consideration the different developmental stages of the child and psychosocial issues that are related to their parents and family.[1] Paediatric palliative care in the community provides primary care doctors a challenging opportunity to improve their knowledge and skills in palliative care to expand their role in the community.

CASE PRESENTATION

A 7-year-old boy diagnosed with advanced medulloblastoma with multiple spinal metastases was referred for palliative care in the community setting. Several home visits were made to assess his clinical condition and to palliate his symptoms. His mother's main concern at the time of referral was his uncontrolled pain at the neck region, especially worse on movements. Patient was not able to describe his pain in detail. Gradually, he developed progressive weakness of both upper and lower limbs bilaterally and urinary and faecal incontinence. He was upset and irritable. His mother did not give him the analgesics which were prescribed by the Paediatric oncologist. Instead, she gave him traditional medicine which did not relieve any of his symptoms.

The patient was not informed of the diagnosis by his parents. Instead, he was told that he had a 'worm' in his head that made him sick. Patient had surgery done, and had received radiotherapy and chemotherapy treatment for the medulloblastoma but there was no response of the tumour to these treatments. His symptoms became progressively worse and caused him to feel very frustrated. He had initially enquired about his illness, but later stopped asking when he found that he was not improving.

Patient's mother stopped working to take care of him full time. His father appeared detached and preferred not to be involved when we kept him informed of the progress and management options for his son. Patient's siblings knew about his condition but felt quite neglected because of the amount of time and attention required by the patient from their mother.

On clinical examination, patient appeared thin and small for his age. He was irritable and it was difficult to establish a good rapport with him at our first home visit. However, he was able to respond to our questions and gave relevant answers. Examination of the spine showed some tenderness over T1 vertebra. The overlying skin appeared normal and there were no palpable masses or spinal deformities. He was able to move both his upper and lower limbs, but power was reduced to grade 4/5 for upper limbs and 3/5 for lower limbs. Subsequently, he developed a distended bladder with overflow incontinence and laxity of the anal sphincter.

Over the next few visits, we managed to convince patient's mother that she had to administer the prescribed analgesics to patient on a regular basis. A simple analgesic, paracetamol was used. With the aid of the Wong-Baker Faces scale (a paediatric pain scale), the patient revealed that with paracetamol, his pain score improved from 6/10 to 2/10. However, the pain score increased to 9/10 when he was being moved. Patient was referred to an occupational therapist that recommended a soft collar to offer more support to the cervical region, and taught patient's mother the correct techniques of positioning and moving him. This dramatically reduced the patient's incidental pain.

Based on the history of spinal metastases and decreasing muscle power, urinary retention and loss of bowel control, a clinical diagnosis of spinal cord compression was made. An indwelling urinary catheter was inserted and manual evacuation of the rectum was performed under sedation at home. Oral dexamethasone was prescribed for its anti-oedema effect to delay the progression of symptoms from spinal cord compression. A loading dose of 0.5 mg/kg was used. When patient showed improvement, the dose was tapered off gradually every three days.

As patient did not ask further about his diagnosis, the issue of conspiracy of silence was not pursued. Patient's mother was consistently kept informed of the clinical progress of patient's medical condition. Anticipated complications and plans of management were explained and discussed with her. Arrangements were made for loan of hospital equipment such as a hospital bed and commode for convenience in nursing care. Patient's pain and discomfort were reduced significantly. He passed away peacefully one week later.

DISCUSSION

A holistic and multidisciplinary approach is of utmost importance in palliative care to alleviate the patient's physical, psychological and social distress, as well as providing support for family members. It is more challenging when palliative care is required for children who have different needs as compared to adults. The different psychosocial developmental stages of children in their perception of death and dying, difficulties of symptom assessments and management, and the impact of the child's sufferings on the family have to be taken into consideration. It is important for the health care provider and the parents to realize that the primary aim would now be the patient's quality of life rather than attaining cure for the disease itself.

Many parents prefer their child to be cared for in the home setting rather than in the hospital.[2] However, home-based palliative care is not well established as yet in Malaysia.[3] This type of service is mainly provided by non-governmental organizations in urban areas.[3] Shared care between palliative care physicians and primary care doctors can improve access to such services, as how it is currently being practiced in United Kingdom and Australia.[4,5]

Assessment of pain in children is a challenging task. Paediatric pain scales, paediatric dosing and guidelines from World Health Organisations (WHO) pain ladder are useful for pain management in children.[6] Use of opioids is appropriate if pain is severe.[6] Adjuvant analgesics such as anticonvulsants like gabapentin is beneficial for neuropathic pain.[6] In this case, the parents' fear of adverse effects of painkillers was a major barrier to use of adequate analgesics to achieve good pain control. Educating the parents on the safety of painkillers and benefits of good symptom control together with supportive occupational therapy helped to alleviate the patient's pain.

Collusion or conspiracy of silence is common in palliative care. A child may also want to know the diagnosis and what he is going through. It is recommended that the child should be informed; the extent of details to be given is determined by the psychosocial developmental stage and level in understanding of the child, and information is to be conveyed in appropriate manner according to the child's age.[7]

Establishment of a good rapport with the child is important. Patient had been traumatized by his bad experiences while receiving treatments in the hospital. His lack of cooperation at the first few home visits posed difficulties for us to conduct a proper clinical assessment on him. Gradually, after getting to know us, he became less withdrawn and more co-operative. Winning over the child's trust in us helped to enhance his mother's trust and confidence to follow our instructions in palliating the patient's symptoms. This led to improved compliance and better clinical outcome.[8] In order to build a good rapport with children, we have to come down to their level to seek a common ground with them to learn more about their interests and preferences.

Good communication skills, showing compassion, honesty and being available anytime for them to ask questions will help patients and their family to go through this difficult time.[9] Providing hope, information and supportive advice to the family will help them to cope with the situation on day-to-day basis. Although patient's father was not willing to participate in our discussions, it was important to let him know that we were available for discussion whenever he felt ready to do so. Patient's mother, being the main carer and decision maker needed full emotional support.

Principles of Family Medicine namely primary contact, comprehensive and patient oriented care, good communication skills and good doctor-patient relationship are beneficial to primary care doctors in providing palliative care in the community.[4,10] However, primary care doctors require further training in managing chronic pain and other physical symptoms in the palliative care setting, and training in communication skills on how to handle difficult issues such as breaking bad news, collusion, uncertainty of giving time frame and bereavement support.

Future vision of primary care doctors providing home palliative care is faced by challenges such as lack of training opportunities, lack of qualified palliative care consultants, limited resources and high workload in the general practice setting.[5,10] Primary care doctors with special interest in this area can benefit from training workshops conducted by non-governmental organizations and work towards greater partnership with hospital-based palliative care services.[3]

CONCLUSION

The prospect of providing palliative care for children is challenging as there is lack of knowledge and expertise in this field in Malaysia. Primary care doctors have great potential to offer such care to the community in view of their strengths in offering comprehensive and personalized care, better accessibility, good communication skills and better rapport, and the ability to coordinate services for the patient and the family.

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Smoking is common in male and female students in a private university

Al-Naggar RA, Al-Dubai SA, Al-Naggar TH, *et al.* Prevalence and of smoking and associated factors among Malaysian university students. *Asian Pac J Cancer Prev*. 2011;12(3):619-24.
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This is a cross-sectional study of 199 students (102 males, 97 females) in the Management and Science University (MSU). The smoking prevalence (based on self-report) is 29% (41.2% in males and 17.5% in females).