

## **Clinical spectrum of children receiving palliative care in Malaysian hospitals**

### **ABSTRACT**

**Introduction:** Awareness for paediatric palliative care has resulted in the impetus for paediatrician-led palliative care services across Malaysia. However, there is paucity of local data on patients receiving hospital-based paediatric palliative care. We aim to review the clinical spectrum of patients referred to these services.

**Methods:** An observational study of children aged between 0-18 years receiving palliative care at 13 hospitals between 1st January and 31st December 2014 was carried out.

**Results:** There were 315 patients analysed, 90 (28.6%) and 46 (14.6%) were neonates and adolescents respectively. The main ICD-10 diagnostic categories for all patients were identified to be 'Congenital malformations, deformations and chromosomal abnormalities' 117 (37.1%), 'Diseases of nervous system' 76 (24.1%) and 'Neoplasms' 60 (19.0%). At referral 156 (50%) patients had holistic needs assessments. Patients with 'Diseases of nervous system' were assessed to have significantly more physical needs than the other two diagnostic categories. Majority of patients who knew of their diagnosis and prognosis were those with malignancy. Over a fifth of referrals were at their terminal admission. Of 144 who died, 111 (77.1%) had advanced care plans. There was bereavement follow-up in 98 (68.1%) patients.

**Conclusion:** Patients referred for palliative care have varied diagnoses and needs. To ensure all paediatricians are competent to deliver quality care to all children, further education and training initiatives is imperative.

**Keyword:** Hospital-based care; Malaysia; Paediatric; Palliative care; Palliative care diagnoses