

## **Paediatric palliative care at home: a single centre's experience**

### **ABSTRACT**

**INTRODUCTION:** There is increased awareness of paediatric palliative care in Malaysia, but no local published data on home care services. We aimed to describe the paediatric experience at Hospis Malaysia, a community-based palliative care provider in Malaysia. **METHODS:** We conducted a retrospective case note review of patients aged up to 21 years who were referred to Hospis Malaysia from 2009 to 2013. **RESULTS:** A total of 137 patients (92 male, 45 female) with a median age of 140 (36250) months were included in this study. The majority (71.5%) had malignancies. At referral, 62 patients were still in hospital and 17 died prior to discharge. A total of 108 patients received home visits. At the first home visit, 89.8% of patients had at least one physical symptom. Pain was the most common (52.5%) symptom. Patients had various supportive devices: 39 were on feeding tubes, ten had tracheostomies, five were on bilevel positive airway pressure and ten had urinary catheters. 66 families discussed the preferred location of care at end-of-life. Among those who died, 78.9% died at home, as they preferred ( $p < 0.001$ ). Regression analysis showed no statistically significant association between a home death and age, diagnosis and number of home visits. Bereavement follow-up occurred for 93.3% of families. **CONCLUSION:** Community care referrals tend to occur late, with 25.5% of patients dying within two weeks of referral. At referral, patients often had untreated physical symptoms. The majority of families preferred and had a home death.

**Keyword:** Home care; Location of death; Paediatric; Palliative care