

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

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**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 (3–250) 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.

Keywords: home care, location of death, paediatric, palliative care

## INTRODUCTION

Palliative care was formally introduced in Malaysia in the 1990s, mainly for adult patients with cancer.<sup>(1)</sup> Since then, the understanding of palliative care has evolved and specialist palliative care is now recognised as holistic care provided by an interdisciplinary team to those with life-limiting illnesses.<sup>(1,2)</sup> Palliative care for children has recently received attention in Malaysia. This may be due to a snowball effect from the development of adult palliative medicine, as well as from paediatricians interested in improving care for their patients. There has also been governmental support in the development of paediatric palliative care. In 2012, the Malaysian Minister of Health launched the National Paediatric Palliative Care Policy to formalise services.<sup>(3)</sup>

Palliative care is active care, extending to bereavement care, that can be provided together with life-prolonging therapies at hospitals, in the community or at patients' homes.<sup>(2)</sup> Paediatric palliative care aims to relieve suffering and enhance quality of life for infants, children and adolescents with life-limiting illnesses and their families.<sup>(2,4)</sup> Home care is a vital component of palliative care, as many patients spend a large part, especially the last six months, of their life at home.<sup>(4,5)</sup> A home death has been reported to be preferred by patients and their families, with benefits to parental outcome, and is often an indicator for good end-of-life care.<sup>(6-8)</sup> Hence, it is essential to integrate home care services with services that provide palliative care.

Due to the diverse spectrum of paediatric life-limiting diagnoses and illness trajectories, care should be patient- and

family-oriented.<sup>(9,10)</sup> Children with chronic complex diseases are surviving longer with improved medical technology and some of these patients would benefit from palliative care.<sup>(11)</sup> Currently, paediatricians in Malaysia mainly provide palliative care in hospitals and existing adult-based community palliative care services are expected to provide home care. Hospis Malaysia is a non-government, community palliative care provider for both adults and children living within the Greater Kuala Lumpur (Klang Valley) area in Malaysia that, based on 2013 population figures, covered an estimated resident population of about seven million.<sup>(12)</sup> Hospis Malaysia receives patient referrals from doctors and accepts patients with a life-limiting illness and who live in the service coverage area. Carers are contacted within the next working day. In this study, we aimed to describe our experience in order to better understand the local need for paediatric palliative care.

## METHODS

This was a retrospective review of case notes of all patients up to 21 years of age who were referred to Hospis Malaysia from 2009 to 2013. The study was approved by the Hospis Malaysia Ethics Committee. Demographic data of all patients accepted to the service was collected and further clinical data from patients who had received home visits was obtained. Descriptive, cross-tabulation and regression analyses were carried out. All statistical analysis was conducted with IBM SPSS Statistics version 21.0 (IBM Corp, Armonk, NY, USA).

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## RESULTS

A total of 141 patients were initially identified for inclusion in the study. However, four patients whose case folders were missing were subsequently excluded. Finally, 137 patients (92 male, 45 female) with a mean age of 140 (range 3–250) months were included in the review. There was a general increasing trend in referrals over the five-year study period (Fig. 1). Data from these 137 patients was analysed (Fig. 2) and the patients' characteristics are presented in Table I.

The majority of referrals were from university and Ministry of Health hospitals (Table I). At referral, 62 patients were inpatients and 17 died prior to discharge. Carers were contacted within the next working day for 97 (70.8%) patients. Out of the 137 patients, 108 received home visits and the median time from referral to a home visit was 5 (0–92) days. On average, patients were visited or contacted every nine days and 48 families used the 24-hour emergency on-call service. At the first home visit, 97 (89.8%) of the 108 patients had at least one physical symptom, although the majority had two symptoms (Fig. 3). Pain was the most common symptom, occurring in 51 (47.2%) patients, of whom 25.5% were in severe pain (self-reported or as assessed by the visiting health care professional). Despite having pain, nine patients were not prescribed any analgesia by the referring doctor. Of all 108 patients who received a home visit, 39 (36.1%) were on feeding tubes (31 on nasogastric tubes and eight on gastrostomy tubes), 10 (9.3%) had tracheostomies, 5 (4.6%) were on noninvasive ventilation (bilevel positive airway pressure) and 10 (9.3%) had indwelling urinary catheters.

Discussions on their preferred location for end-of-life care occurred in 66 families. Of those who died during the study period and preferred a home death, 78.9% ( $n = 30$ ) died at home ( $p < 0.001$ ) (Table II). Regression analyses showed no statistically significant association between a home death and age, diagnosis and number of home visits. The median duration of end-of-life care for patients with cancer was almost eight weeks (range 1–832 days) and 22 weeks (range 6–1,812 days) for patients with noncancer diagnoses. At the end of the study, 16 patients were discharged as eight were clinically stable, six families moved out of the coverage area and were referred to other palliative care services if available, and two patients had prolonged hospital admission. The majority (93.3%,  $n = 70$ ) of families had at least one bereavement follow-up.

## DISCUSSION

This study investigated patients who were referred for home care in the Greater Kuala Lumpur (Klang Valley) area, their families' use of services and patients' location of death. Home care requires close collaboration between primary paediatricians and service providers to ensure a smooth transition and continued care at home. In a recent study, the most common barrier to referral in Malaysia was found to be the perceived lack of accessible services.<sup>(13)</sup> This study revealed the encouraging finding that some paediatricians in private practice are referring their patients for palliative home care. The small referral numbers may be a reflection of the nature of illnesses they treat. However, it

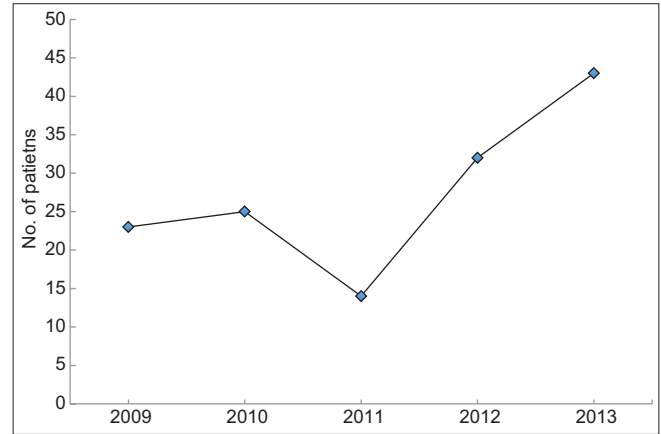


Fig. 1 Graph shows the number of patient referrals by year.

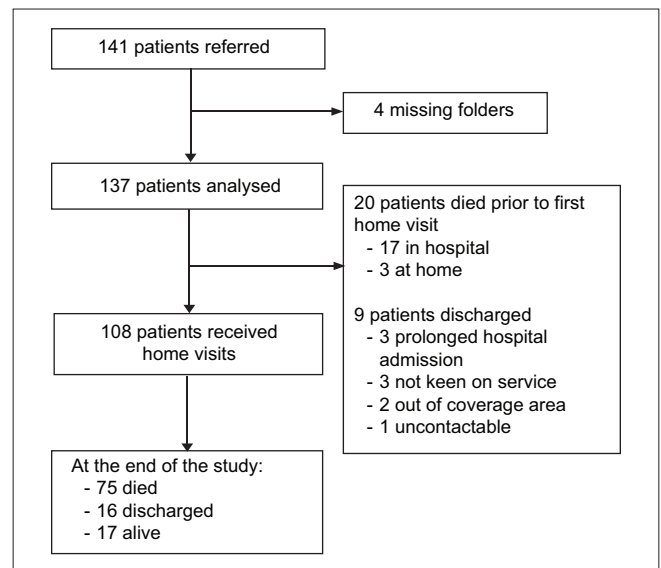


Fig. 2 Flowchart shows details and outcomes of patients who were referred.

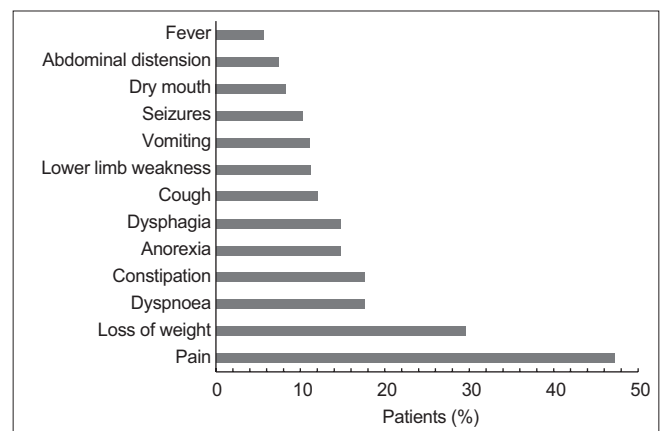


Fig. 3 Bar chart shows patients' symptoms at the first home visit ( $n = 108$ ). Symptoms occurring in less than 5% of patients are not included.

is important that all paediatricians are aware of the palliative home care service in their patients' area. Programmes to increase awareness and promote integration of palliative care services need to be strengthened.

As in other studies, the majority of referrals to home care are for children with cancer.<sup>(14,15)</sup> Prevalence studies, however, show

**Table I. Characteristics of patients referred (n = 137).**

Parameter	No. (%)
<b>Gender</b>	
Male	92 (67.2)
Female	45 (32.8)
<b>Source of referral</b>	
Ministry of Health hospital	55 (40.1)
University hospital	65 (47.4)
Private hospital	17 (12.4)
<b>Diagnosis</b>	
Cancer (n = 98)	
<i>Leukaemia/lymphoma</i>	26 (26.5)
<i>Brain/central nervous system</i>	20 (20.4)
<i>Sarcoma</i>	15 (15.3)
<i>Osteosarcoma</i>	13 (13.3)
<i>Other</i>	24 (24.5)
Noncancer* (n = 39)	
<i>Congenital malformation/deformation/ chromosomal abnormality</i>	13 (33.3)
<i>Disease of the nervous system</i>	12 (30.8)
<i>Metabolic disease</i>	6 (15.4)
<i>Neurodevelopmental disorder</i>	5 (12.8)
<i>Other</i>	3 (7.7)

\*Diagnoses based on the International Classification of Diseases, tenth revision, clinical modification.

that cancer does not represent more than 25% of life-limiting diagnoses.<sup>(10,16)</sup> There is a lack of awareness of the palliative care needs of children with noncancer diagnoses or a misconception of palliative care. Reluctance to refer may also be due to the uncertainty of the prognosis or the family's reluctance to accept palliative care.<sup>(13,17,18)</sup> Many patients in this study were referred when they were in the terminal stages, with 25.5% of our referral patients not living beyond two weeks, and the majority of these referred children had cancer. It was not within the scope of this study to ascertain the reason for late referrals of this population, but it is important for future research. The median duration with the service for children with cancer was less than eight weeks, as compared with 22 weeks for noncancer patients. For patients with cancer, referrals occurring at the end-of-life may be due to the more predictable disease trajectory, when incurability is clinically obvious.<sup>(19)</sup>

There is currently no Malaysian data on the prevalence of noncancer, life-limiting illnesses in children. The duration with the service for these patients was wide, ranging from six to 1,812 days. This reflects the variable clinical trajectory of noncancer diagnoses, which have prolonged and fluctuating palliative care needs. In contrast, adults tend to have a shorter period of palliative care services.<sup>(20,21)</sup>

There are almost 400 diagnoses that should receive palliative care and the World Health Organization recommends that children should receive palliative care at diagnosis.<sup>(2,10)</sup> General paediatricians and primary specialists need to provide general palliative care, as there are few specialist palliative care providers and resources are limited.<sup>(5,22)</sup> Hence, it is imperative to educate all

paediatricians on basic palliative care to meet the needs of their patients. To cope with limited organisational resources, patients were discharged after their palliative care needs were addressed and when they were clinically stable. These patients continued to receive care from their primary specialist, who could provide further referral when necessary.

Reports show that even patients who received specialist treatment may experience distressing symptoms at end-of-life.<sup>(6,23,24)</sup> In this study, pain was the most common symptom present at referral and a few of these patients did not receive analgesia. The ability to recognise symptoms and education on symptom control are urgently needed for healthcare professionals. Unfortunately, data collected did not allow the assessment of symptom control at end-of-life for the 75 patients who died during the study.

Discussions on location of death may have influenced the patients' actual place of death, as 80.0% (n = 32) of patients who indicated a preferred location died in the location of their choice; this finding is similar to that in a previous study.<sup>(14)</sup> Home deaths occurred in 78.9% of families who had discussions, compared to 46.2% among families who had no discussion, although it is not clear if these two populations are comparable. It is important to note that studies show that early involvement of home care and effective communication facilitate death at the desired location, although evidence on the families' preference of a home death is unclear.<sup>(25,26)</sup> Nevertheless, the opportunity to plan the location of death has been reported to reduce parental regret about the location of death, which may be a better reflection of good end-of-life care than the frequency of home death.<sup>(25)</sup> More studies are needed to explore this aspect of end-of-life care.

In this study, families were visited or contacted by phone every nine days on average. However, 24-hour access was available for carers, who used this for queries about physical symptoms and emotional support. The continuous availability of palliative care support for patients and carers is an essential component of a home care service. Preparing and helping patients and carers anticipate symptoms or issues that may arise at various times in their illness may help reduce the number of emergency calls. Adult studies have shown that increased visits from family physicians or palliative care providers reduce hospital emergency department visits and admissions.<sup>(27,28)</sup>

Some patients in this study were sent home with additional, complicated technological support devices, which may be an increasing trend with medical development. To support the families, home care providers will need to be competent in managing these devices.

There were several limitations to this study. Retrospective data collection limits the quality of information collected, and interpretations and assumptions from these results may not apply to other populations in Malaysia. This study did not examine how parents chose the location of care and further studies could explore this aspect of end-of-life care.

In conclusion, this study provides some insight into the practice of paediatric palliative care in Malaysia. The majority of referrals were for children with cancer. Education and awareness

**Table II. Actual and preferred location of death of patients who died during the study period (n = 75).**

Discussion on location of care at end-of-life	Location of death				
	Home	Hospital	GP clinic	In transit	Nursing home
<b>No (n = 26)</b>	12 (46.2)	12 (46.2)	1 (3.8)	1 (3.8)	0
<b>Yes, preferred location indicated (n = 49)</b>					
Home (n = 38)	30 (78.9)	7 (18.4)	0	1 (2.6)	0
Hospital (n = 1)	0	1 (100)	0	0	0
Nursing home (n = 1)	0	0	0	0	1 (100)
Unsure (n = 9)	1 (11.1)	8 (88.9)	0	0	0

Data presented as no. (%). GP: general practitioner

about palliative care for all children with life-limiting illnesses is necessary. Referrals tend to occur at advanced stages of diseases, but identification and assessment of palliative care needs can help reduce late referrals. The management of pain and other symptoms is also not well-recognised and managed. Discussions on advanced care plans and location of end-of-life care need to occur at the earliest appropriate opportunity. Resources such as staff and the ability to provide 24-hour continuous care should be taken into consideration in all home care services.

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