

# Clinical spectrum of children receiving palliative care in Malaysian Hospitals

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## 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.

## KEY WORDS:

*Paediatric, palliative care, Malaysia, hospital-based care, palliative care diagnoses*

## INTRODUCTION

In Malaysia, palliative care has been in existence since the 1990s but palliative care for children is still in its infancy.<sup>1</sup> Provision of paediatric palliative care in Malaysia had

initially been ad hoc by individual paediatricians in hospitals and by non-governmental organisations (NGOs) in the community.<sup>2</sup> In 2012, the Ministry of Health acknowledged the importance of palliative care for children and launched a National Paediatric Palliative Care Initiative that aims to enable children access to palliative care.<sup>3</sup> The World Health Assembly, in 2014, has also recognised palliative care as an essential component for quality health care.<sup>4</sup> These events and concurrent increasing awareness among Malaysian paediatricians, has led to coordinated efforts to try improve paediatric palliative care services, especially in hospitals.

The number of children in Malaysia with palliative care needs is unknown. A recent publication showed the prevalence of children with life-limiting conditions to be 32 per 10,000 children.<sup>5</sup> From this estimate, there could be about 25,000 Malaysian children who could have palliative care needs.<sup>6</sup> Children with advanced life-threatening conditions often spend long periods in hospitals where their illness and symptoms are being treated; and palliative care is often introduced there.<sup>7-9</sup> While there are reported studies of experiences of hospital-based paediatric palliative care services in North America, it's unknown how palliative care referrals in Malaysia compares.<sup>10-12</sup> Hence we conducted this study of patients receiving palliative care from 13 hospitals around Malaysia over a one-year period from January to December 2014. We aim to describe the demographics, diagnoses, clinical spectrum, prognosis of referred patients and the challenges of providers of their hospital-based services in Malaysia. We hope this pilot study will provide healthcare providers and policy makers with better understanding of children currently receiving palliative care as we plan for a national strategy.

## MATERIALS AND METHODS

Paediatricians who lead palliative services from 15 hospitals were identified through various local paediatric networks as well as at national paediatric and palliative care meetings. To the best of our knowledge this is an accurate representation of hospital-based palliative care services at the

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time of this study. Of the 15 services, paediatricians leading 13 services agreed to be study coordinators. They were all from Ministry of Health hospitals.

This is an observational cross-sectional study conducted between 1st January and 31st December 2014. All patients aged up to 18 years old who received palliative care services at these 13 hospitals were included. Ethics approval for all hospitals was obtained from the Medical Research and Ethics Committee of the Malaysian Ministry of Health (NMRR-14-1005-21506).

Study coordinators at each hospital reviewed the medical case notes of their patients and entered anonymised data in a standard study proforma created for this study. Data collected included demographic information of patients (participating hospital, age, gender, ethnicity, nationality, siblings and main caregiver), clinical data (underlying diagnosis with the International Statistical Classification of Diseases 10th revision (ICD-10) code, referrer specialty, reason for referral), assessment at referral (needs assessment, patient and caregiver understanding of diagnosis and prognosis), follow up management (end of life care discussions, number of hospital admissions one year prior to death, bereavement follow up) and service data (challenges faced by services, extent of service provided, funding for service). Data from all study coordinators was sent to the principal investigators and a master database compiled. The master data was reviewed and patients were excluded if vital missing data was unobtainable from the respective study coordinators.

From the final master database, descriptive analysis was used for demographic data, cross tabulations for comparisons of patients' groups and characteristics; and survival analysis with log-rank test was used to compare time to death from referral between diagnostic categories. Analyses were carried out with IBM® SPSS® statistical software version 21.

**RESULTS**

*Characteristics of the patients*

Data from 329 patients were collected from 13 hospitals. Date of birth was unobtainable from 14 patients, leaving 315 patients in the study. Of these 315 patients, 254 patients were new referrals during the study period while the other 61 patients were existing patients from the respective services. Five of 315 patients were referrals for bereavement care for families following death of the patient.

More than a quarter of the patients were neonates and there were 46 (14.6%) patients above 12 years of age (Table I). Mothers were the primary caregivers in 216 (70.8%) patients. Almost three quarters of patients had siblings (Table I).

Majority (94.3%) of referred patients were from within the participating hospitals. Referrals were mainly from general paediatricians 200 (63.5%), followed by oncologists 42 (13.3%) and neonatologists 26 (8.3%).

The three most common diagnostic categories by ICD-10 were i) Congenital malformations, deformations and

**Table I: Demographics of patients referred (N = 315)**

	n (%)
Age	
Neonates <28 days	90 (28.6%)
Infants 29 days to 12 months	51 (16.2%)
13 months to 12 years	128 (40.6%)
13 years to 18 years	46 (14.6%)
Gender	
Female	133 (42.0%)
Male	182 (58.0%)
Ethnicity	
Malay	182 (57.8%)
Chinese	58 (18.4%)
Indian	21 (6.7%)
Indigenous	46 (14.6%)
Others	8 (2.5%)
Nationality	
Malaysian	310 (98.4%)
Non-Malaysian	5 (1.6%)
Main Caregiver (N=305)	
Mother	216 (70.8%)
Both Parents	58 (19.0%)
Father	12 (3.9%)
Others	19 (6.3%)
Patients with siblings (N=307)	
Yes	226 (73.6%)

chromosomal abnormalities: 117 (37.1%), ii) Diseases of the nervous system: 76 (24.1%) and iii) Neoplasms: 60 (19.0%) (Figure 1). In the category of 'Congenital malformations, deformations and chromosomal abnormalities', the most common diagnosis was Trisomy 18 with 23 (19.7%) patients and the most commonly affected organ system in this category was cardiovascular system 45 (35.0%) patents. In the category of 'Diseases of the nervous system', the three most common diagnoses were cerebral palsy, 31 (40.7%) patients; spinal muscular atrophy, 15 (19.7%) patients; and Duchenne muscular dystrophy, eight (10.5%) patients. Acute lymphoblastic leukaemia was the most common malignancy in this study.

The two most common specific reasons for referral other than for 'palliative care' was for 'end-of-life' care 132 (41.9%) and 'symptom' control 55 (17.4%). Of the 310 patients who were referred, assessment for palliative care needs showed that physical assessments were done most frequently in 276 (99.3%) patients, followed by emotional and psychosocial assessments in 230 (83.3%) and 228 (82.3%) of patients respectively. Assessment of spirituality was done in less than two thirds of the time. Half of all patients (156) were assessed in all four domains. Of patients assessed in the physical domain, 230 (82.7%) had symptoms (Figure 2). Patients in the ICD-10 diagnostic category of 'Diseases of the nervous system' had more physical needs than 'Congenital malformation, deformations and chromosomal abnormalities', and 'Neoplasms' categories (OR=3.95, 95% CI 1.47 to 10.61, p<0.01). There was no statistically significant difference in psychosocial or emotional needs between the three most common diagnostic categories of disease.

All caregivers were aware of the diagnosis and prognosis of the patient. Of 41 patients who were perceived to know their diagnosis, only 26 were aware of the prognosis (p<0.01).

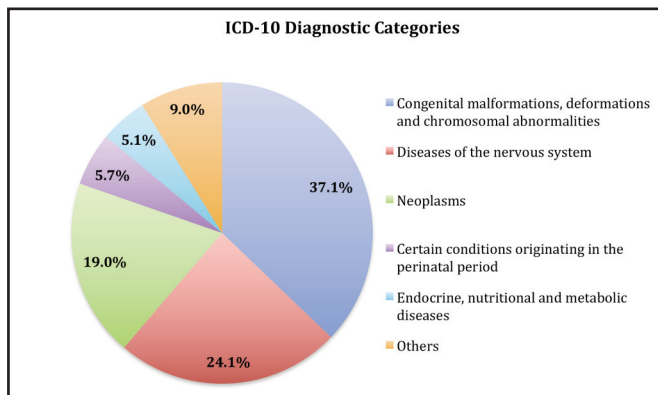


Fig. 1: Diagnoses (ICD-10 Diagnostic Categories) of all patients (N=315).

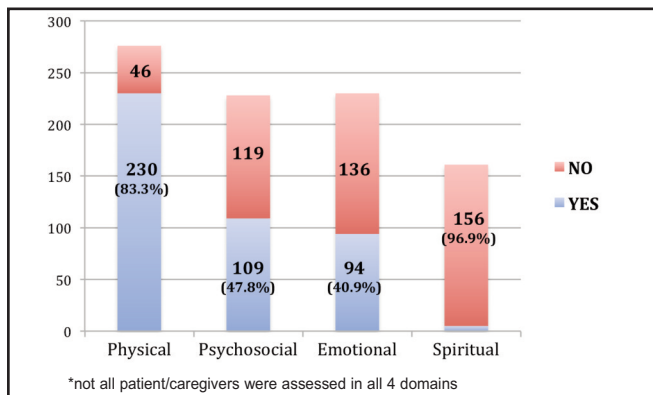


Fig. 2: Presence of palliative care needs following assessment in the 4 domains. (N=310\*).

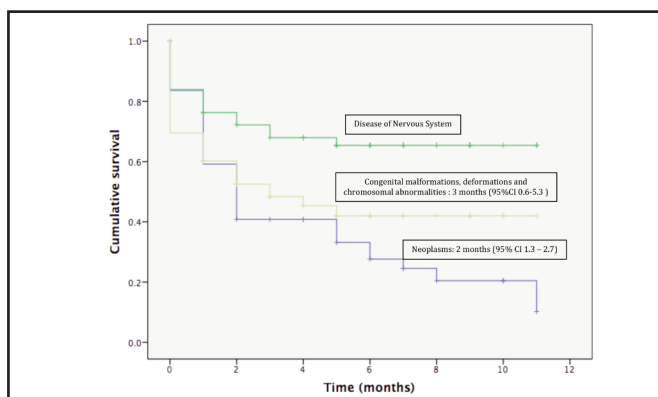


Fig. 3: Median survival of patients from referral between the three most common diagnostic categories. (P<0.01).

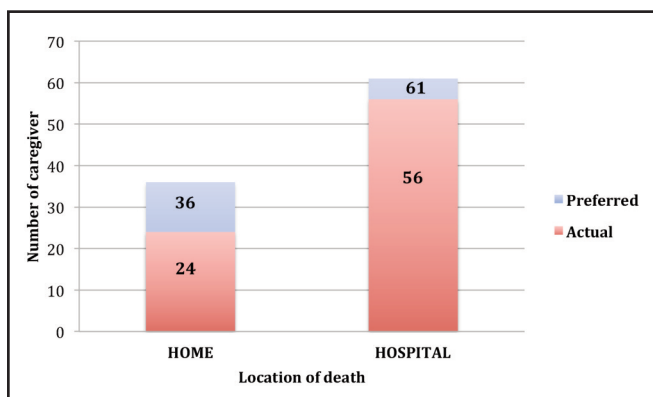


Fig. 4: Preferred and actual place of death for caregivers of patients who died.

Over a fifth 68 (21.6%) of referrals were made at patient’s terminal admission. The median time from referral to death for this group of patients is two days (range 0-182) and six days (0-222) in the neonatal and non-neonatal group respectively.

There were 144 patients who had died at the end of the study period with 73 dying in hospital and 35 at home.

Survival analysis for the three main diagnostic categories showed a median time to death of three months and two months for ‘Congenital malformations’ and ‘Neoplasms respectively’ (Figure 3). Advanced care plans and resuscitation plans were discussed with either patient or caregiver in 111 (81.6%) and 124 (91.2%) respectively. A quarter of caregivers had discussions about funeral preparations with health care staff. On the desired location of care at end-of-life, 97 (73.4%) of caregivers had opportunity for discussions (Figure 4).

Following patient’s death, 98 (68.1%) of families had a follow-up phone call and 52 (36.1%) were met in person for bereavement follow-up.

*Characteristics of the services*

Ten services officially started in 2013 and 2014. The other three services started in 2006, 2009 and 2012. The number of

patients from each of the 13 hospitals ranged from six to 61 patients. Majority (10) of the service providers were general paediatricians. Two paediatric oncologists and a neurologist led the other three services.

Four hospitals provided only hospital-based consultative services. The other nine hospitals also did home visits or collaborated with community services to provide home care for their patients. Ten hospitals relied on existing department funding to run their service. Three services received additional funding from NGOs and government sources. Two services reported receiving no additional funding to run their service.

The challenges identified by hospital-based service providers could be categorised into three areas; i) issues from healthcare professionals, ii) perceived unmet families’ needs and iii) issues related to the healthcare system. Health care professionals felt they needed more knowledge and skills in symptom management, challenging communications, dealing with families who collude and addressing families concerns at the end-of life. Coordinating care with other health care professionals was challenging and not being able to speak the language of families also hindered their care. Families’ needs arise from financial assistance, respite care, equipment to aid in care and support for the siblings of their sick child. There was also the perceived lack of trained staff in

general to provide palliative care. Community and home support after discharge as well as the patient's geographical distance from hospital compromised care.

## DISCUSSION

This is the first published report on hospital-based paediatric palliative care services in Malaysia. As palliative care services for children are being developed locally, we hope that results of this study will enhance understanding of service needs and challenges.

More than a quarter of referrals were neonates, which is higher than previously reported studies. A small proportion, less than a fifth, of patients in this study were above 12 years of age. In some Malaysian hospitals, these adolescents may be seen by adult healthcare services. The spectrum of diseases from this study is similar to previously reported studies; with congenital conditions, disease of nervous system and malignancy being the common three diagnostic groups.<sup>10,11,13</sup> This confirms patients with palliative care needs have a variety of diagnoses and are cared for by many different paediatric subspecialists and other healthcare professionals. American Academy of Pediatrics had proposed the importance of an integrated model of palliative care that runs alongside curative treatment to maximally support patients with life threatening or life limiting illnesses.<sup>14</sup> Plans to develop this service will need training and resource allocations for multi-disciplines. This also highlights the need for collaboration within paediatric subspecialties, foeto-maternal medicine specialists, allied health care professionals and adult services for coordinated care especially in a resource limited health care system.

In understanding referral patterns, the two common reasons for referral, other than for general 'palliative care', were end-of-life care and symptom control. Perhaps knowledge and skills training in these two areas will need to be prioritised.

This study also reveals that in assessment of palliative care needs, assessment of physical domain is often done. The majority of patients 230 (83.3%) had physical symptoms when assessed at referral. Palliative care teams need to have a broad understanding of the diverse physical symptoms from the varied diagnoses of patients with life-limiting illness. Equally as important are psychosocial, emotional and spiritual symptoms. Hence assessment for palliative care needs requires a holistic approach. A previous local study of bereaved parents of children with life-limiting illnesses revealed that they not only perceived inadequate symptom control for their children but there was also poor communication and lack of anticipatory guidance in care.<sup>15</sup> It is interesting that palliative care providers in this study also expressed lack of knowledge and skills in managing challenging communications with families and untrained in addressing parents' concerns at end-of-life.

It's encouraging that all caregivers in this study knew the diagnosis and prognosis of the patient. However, patient's understanding of illness and prognosis and the possibility and impact of collusion will need to be furthered explored in future studies.

While not explored in this study, support for carers and siblings is an important aspect of palliative care and may reduce their risk of poor emotional health and psychological health in the future.<sup>7,16,17</sup> The negative impact on carers has previously been documented and home-based respite care has been highly valued.<sup>1</sup> Development of community and social support is a vital part of good palliative care service. In this study population, almost three quarters of patients have siblings and thus services to develop sibling care will also need attention.

Often, preferences on the location of death are explored with caregivers as part of the advanced care plans. From this study, more caregivers 61 (62.9%) preferred end of life care in hospital rather than at home. It is unknown if the option of support for a home death was available for these families. It has been noted that the decision for the location of death is complex.<sup>19</sup> Further studies are needed to explore preference for location of death and their reasons. For caregivers who preferred a home death, 24 (66.6%) achieved it compared to 56 (91.8%) of those who preferred hospital deaths. Realistic options for patients to have seamless care and support in the community needs more attention.

In this cohort, the median time from referral to death for terminal admissions is less than a week. Referrals at terminal diagnosis may deprive patients and families of the holistic support throughout their disease trajectory. Further studies are needed to understand the possible barriers to referral despite having the access to a palliative care service. A previous study of Malaysian healthcare professionals suggested that family's goals and expectations may influence referral for palliative care.<sup>2</sup> There is also a need to educate and promote palliative care as more than just end-of-life care.<sup>7</sup> Survival curves demonstrate that median survival from referral was shortest for those with neoplasms and patients with diseases of nervous system have a longer survival. Prolonged care is required for this latter group of patients. Palliative care needs of patients with non-malignant diagnoses need to be recognised and acknowledged. Policy makers will need to make provisions for services for these children who require long-term care and more physical support, which have been previously reported.<sup>21</sup>

Palliative care does not end with the patient's death but continues into bereavement.<sup>7</sup> However, only 94 (65.3%) of families received a bereavement follow up in this cohort. There have been reports of consistent benefits of bereavement support for parents and it will need to be incorporated into standard medical care.<sup>22</sup>

In many developing countries, palliative care often focuses on the prevalent life threatening illnesses of the area.<sup>23</sup> Hence Malaysian paediatricians, providing palliative care as a new service, have to understand local needs and geography, to develop the most appropriate model of care. Future studies looking at patients and caregiver's needs and challenges faced by service providers would be useful in developing appropriate palliative care services for Malaysians.

**LIMITATIONS**

Despite this being a consecutive sampling of patients from 13 hospitals representing the diverse population of Malaysian children, one of the limitations of this study is that some data obtained was incomplete and retrospective. This is a pilot study to gather information rapidly to understand current situation to help in service planning. Lack of research funding limited the scope of project. Study coordinators have variable clinical experience and subjective data is dependent on their individual practice. Further understanding of the experience, expectations and outcomes of the palliative care service for these patients and parents will need to be carried out in the future.

**CONCLUSION**

Palliative care in Malaysia is growing with increasing interest among paediatricians. This study demonstrates patients with a variety of life limiting illnesses with different palliative care needs at referral. Neonates represent over a quarter of referrals. Paediatricians and neonatologists pioneering palliative care at their hospitals need training and coordinated support to ensure all children with life-limiting illnesses in Malaysia receive quality care. Providers and policy makers need to share the responsibility to maintain competencies in paediatric palliative care and to address complexities of care and other caregiving challenges. It is imperative that there is a national policy for paediatric palliative care to ensure equitable care.

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