

## ORIGINAL ARTICLE

# Clinical Characteristic of Paediatric Palliative Care Cases in North Eastern of Peninsular Malaysia

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## ABSTRACT

**Introduction:** Paediatric Palliative care has been a relatively new specialty in Malaysia. It serves to cater hospital and community support for children with life-limiting illnesses (LLI). The aim of the study is to describe the clinical characteristic of Paediatric Palliative Care (PPC) cases in the North East of Peninsular Malaysia. **Methods:** Children with LLI were identified through 2 databases captured by the 'Sayangku' Homecare team and Paediatric Palliative Care (PPC) team. These databases include the details on clinical diagnosis, time of referral and outcome. Children included were those referred from November 2012 to March 2020 to PPC service. The number of new cases referred per annum (2019) was compared to the crude estimation of prevalence. **Results:** A total of 216 children were included. About half of the children with LLI (50.5%) were from group 4 and about a quarter from group 1 (27%) of the ACT/RCPCH classification. Approximately one third of our cohort (31%) had died, majority from oncology causes. There were 116 neurology cases, 60 oncology cases and further 48 cases were the remaining cases in our databases. More than one third (37.5%) of the patients were in the age range of 11-18-year-old. The estimated cases under PPC was only 7.7% from the estimated annual prevalence of LLI. **Conclusion:** The current data showed that many of the LLI cases in our area have gone underreported. There is a need to disseminate information and awareness among the medical fraternity on the patient's eligibility for the PPC service.

**Keywords:** Paediatric palliative care, Service development, Paediatrics

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## INTRODUCTION

The first Paediatric Palliative Care (PPC) service in Kelantan has been set up at the end of 2012 through community engagement project between Universiti Sains Malaysia and Kelantan Foundation of Disabled and Underprivileged (YOKUK) partnership (1). The primary PPC team is based at Hospital Universiti Sains Malaysia (HUSM), receiving all referral from the tertiary and the neighbouring district hospitals. HUSM is a known as a tertiary centre in this region with 786 beds capacity and has many sub-specialties training including Paediatric Oncology Service for North East of Peninsular Malaysia. With the project, 'Sayangku' Homecare team has been borne as a community team that served palliative, rehabilitative and education to patients and caregivers. This was done through homecare visits in districts of Kelantan within 40 km radius.

Children account for 37.3% of the Malaysian population and the crude prevalence for children with life limiting

illnesses (LLI) in Malaysia is estimated around 10 in 10000 children (2). There were approximately 672000 children under 19 in Kelantan in 2019 (3). With more than half a million children, the PPC teams require adequate preparation and background information for optimal service delivery. Kelantan has partly suburban area in the district of Kota Bharu and majority of other part of Kelantan can be considered as rural. The information on clinical characteristic and service provided in previous years will allow the team to identify needs and provision for future planning, research and service. The launching of National Palliative Care Strategy for Malaysia (4) has steered guidance and direction nationally. However, with no available national registry for PPC at this stage, incidence and prevalence study of PPC in Kelantan and Malaysia can be difficult. The purpose of the study is to study the characteristic of the clinical cases referred under PPC service in Kelantan using the available information in our databases.

## MATERIALS AND METHODS

Patients were identified from referral made from 2012 - 2020 database from YOKUK Homecare and HUSM hospital database (only from 2018-2020). Referral was made by specific teams either hospital-based

or community-based to PPC specialist at HUSM. Caseloads were based on agreed criteria and diagnosis in the RCPCH/ACT grouping (Table I). Patients will be seamlessly liaised with ‘Sayang’ Homecare Team for follow-up, visitation and palliative care assessment in the community.

**Table I:- Life limiting illnesses classification according to ACT/RCPCH (7)**

Category	Key characteristics	Description	Examples
I	Potential cure – life is threatened, not necessarily limited	Conditions for which treatment may be feasible but can fail	Cancer Cardiac anomaly
II	Period of normality despite having fatal diagnosis	Conditions where premature death is inevitable but where there may be long periods of participation in normal activities	Duchenne Muscular Dystrophy
III	Relentless deterioration from, or before time of diagnosis	Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extend over many years	Metabolic neurodegenerative
IV	Unpredictable course whose progression is not easily judged from natural history	Irreversible but non progressive conditions causing likelihood of premature death through complications	Severe cerebral palsy

### Referral to PPC specialist

Prospective cases were kept by the PPC specialist over the referral period. This includes demographic component, intervention and palliative care problems. Some of the severe cases were managed in the hospital setting without community support, such as Spinal Muscular Atrophy babies that required ongoing medical support only in the hospital setting. Lack of specialised equipment, medication and personnel support during out-of-hours for end of life care would be the limitation in our context.

### Referral to ‘Sayang’ Homecare Teams (YOKUK)

The YOKUK teams provide homecare support and outreach caregiver education such as physiotherapy, occupational therapy and equipment support. The teams are based at Pengkalan Chepa about 5 KM from HUSM. Majority of the children of LLI were referred from Hospital Raja Perempuan Zainab II (HRPZ II), HUSM, district hospitals and healthcare clinics. The team also involved in collaborative partnership with government domiciliary care units for the care of these patients outside the coverage area throughout Kelantan.

Eligible patients were those who were at least 18 year of age and below and diagnosed with LLI by the primary team. Patients requiring palliative care is defined as those who were enrolled under the palliative care and requiring multidisciplinary team support either in the hospital or community settings. Clinical characteristic including demographic data (age at the time of consultation, gender, co-morbidity, diagnosis and source of referral) were recorded.

## RESULTS

There were 114 male and 102 female patients respectively during the period of the study. Majority were between the age 11-18 (37.5%). There were a steady number of referrals from 2012 (2 patients only) and increased up to 52 patients annually in 2019. Two major hospitals which were involved in referring patients for community homecare intervention – namely the HUSM and HRPZ II. Hundred and ninety patients were referred from these tertiary centres. Using ACT/RCPCH categorization, there were 59 patients in group 1, 9 patients in group 2, 39 in group 3 and 107 patients in group 4 respectively (Table II).

**Table II: Demographic data of Paediatric Palliative Care Service in the North East of Malaysia**

Demographic	n (%)		
Gender			
Male	114 (52.8)		
Female	102 (47.2)		
Age			
0-5	64 (29.6)		
6-10	71 (32.9)		
11-18	81 (37.5)		
Year of referral	YOKUK Homecare, n	PPC Team HUSM, n	Total referral, n
2012	2		2
2013	11		11
2014	13		13
2015	42		42
2016	23		23
2017	21		21
2018	25	6	31
2019	32	20	52
2020	11	10	21
Source of referral			
Local tertiary hospital (HUSM)	102 (47.2)		
External tertiary hospital (HRPZ II)	88 (40.7)		
Homecare (YOKUK)	20 (9.2)		
Outside Kelantan	2 (0.9)		
District hospital	4 (1.9)		
Life limiting illnesses group (RCPCH/ ACT)			
1	59 (27.3)		
2	9 (4.2)		
3	39 (18.1)		
4	109 (50.5)		
Outcome			
Died	67 (31)		
Transfer out from PPC team	34 (15.7)		
Move to another state	8 (3.7)		

In term of patients’ distribution, Kota Bharu has the highest number of patients (84), followed by Bachok (26), Pasir Mas (23), Tumpat (23) and Tanah Merah (16) (Figure 1). There were also patients from Terengganu (7) who required palliative care cover. There were mostly non-oncology cases (156 cases) – predominantly were neurology cases (116). Oncology accounted for 60 of the cases under PPC cover during this period (Table III).

## DISCUSSION

This is the first study describing the pattern of PPC



**Figure 1: Relationship number of referrals to geographical location**

**Table III: Type of cases referred for PPC from the hospital and community**

Type of LLI cases referred (2012-2020)	No of cases
Neurology	116
Oncology	60
Genetic	16
Respiratory	8
Cardiology	7
Metabolic	4
Nephrology	4
Other	1

service in the North East of Peninsular Malaysia. Two major tertiary centres in Kota Bharu, namely HRPZ II and HUSM, provide a different spectrum of clinical cases due to the differences in clinical specialty. HUSM provided all paediatric oncology cases and HRPZ II has majority of neurology cases. In the early phase of PPC development, there were small number of patients recorded due to new service, and most effort was used for advocacy and awareness on PPC. Training and clinical engagement between the health care workers are essential component to improve the rate of referral locally (1). There were documented referral and cases from outside Kelantan for PPC service. These cases were mainly from family's personal request to have their child's end-of-life in Kelantan. Many patients were from group 4 of the RCPCH/ACT classification, and the cases in group 2 and 3 were minimally referred. Although there were many cases from group 2 or 3, this has rarely been discussed between the primary team and PPC team. It may be due to lack of awareness on the criteria for PPC referral.

Death was an outcome in approximately 31% of the case. The finding is nearly similar to the finding by children's hospice in Northern England (5). These were documented cases informed by managing team

or community team. There were uncaptured cases from patients moving out from Kelantan and coverage area by the 'Sayang' homecare team. We also did not have the data of family preference on place of death from this study. Most of PPC cases were complex; this posed a challenge for the homecare team to document the complex and fluid information about such cases. Changes in the information may include the changes of symptom management plan, the child wishes plan, advance care planning, letter to the police or domiciliary care and personal resuscitation plan. These were vital piece of management but incomplete in our database.

PPC model in Malaysia is different compared to Western eye view. There are vast differences between primary, secondary and tertiary care in Malaysia and elsewhere. The Malaysian primary care is covered by either private general practitioners or Family Medicine team from the local health clinic. The primary care teams may provide homecare support to family members through domiciliary service or personal home visits. The service provided is mainly nursing, auxiliary and medical in nature without covering on the psychosocial and spiritual aspects of care. Most of experience primary healthcare doctors are reluctant to be the key medical personnel in palliative phase (6) As PPC is a multi-disciplinary team involvement, there are many areas for future improvement for the primary care team. PPC must start from the community where best cared can be provided by the family member in a much loving and cared environment (7). This is because most children with chronic and LLI will spend their time at home. The other aspect would include the challenge in term of frequency of visits, the traveling distance, equipment training and collaboration between team and the government services. The other uniqueness is the rural approach which requires continuous education, modification resources and reinvention of techniques adapted to the individualized environment. The team also provided personal care such as bathing team at home as an added element to the service.

Using the estimated prevalence of LLI in Malaysia (crudely at 10 per 10000), it is estimated that there should be approximately 670 LLI cases for PPC in Kelantan (based cumulative data of children in Kelantan ie 35% of total population of 1.8 million(3)). If 52 annual referral cases in 2019, this indicates only 7.7 percent of the cases were looked after by the PPC team. It is probably that the exact number of PPC cases on the ground is underestimated. Low figure in this study partly the result of under-recognition and under-reporting of children with LLI (7). Underreporting by many of the involving clinicians has contributed to the low number of referred cases. Even if we used lower prevalence (3 in 10000 as per Hain (7)), there should be approximately 200 cases in Kelantan. The chronic PPC patients usually have their own primary team in the hospital who manages treatment before transitioning

over to community care. The primary team has to find appropriate service to support children with LLI in the community. Unfortunately, many primary care teams are not equipped with knowledge and skills to care for these children. Expert has agreed that these children required appropriately trained staffs (5). Without appropriate guidance, parent have to navigate options without much supporting service especially in the rural area. Supporting these family at different disease trajectory phase is warranted to allow a seamless care from the hospital and community. Without adequate cases identified as PPC, optimal service may have yet to be achieved.

In our study, data obtained were taken from the routine data during the referral process. Routine data is supposed to generate information for administrative and clinical process as well as research purpose (8). Other information related to PPC registry, death registry, primary and secondary care data have an inherent value to research and understanding of the service needs. However, it is also important to be aware that these data require safe and ethically sound access, improve and shared linkages for the above purposes.

## CONCLUSION

It is noticeable that many children in Kelantan with LLI are not being care under the palliative care umbrella. Further effort is required to ensure understanding among the referral paediatricians as well as neonatologists, to add to the cohort of the PPC cases. We documented a small number of neonatal cases referred despite the understanding of large number of LLI are identified from the antenatal period. The trend of death in children with LLI for our population perhaps is still unclear. Managing children with LLI in Malaysia requires forging partnership with the family network to ensure sustainability of care locally.

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