ORIGINAL ARTICLE

Characteristics of Paediatric Death Cases at a Malaysian University Hospital

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ABSTRACT

Introduction: Auditing of paediatric deaths has rarely been evaluated in hospitals especially in low and middle-income countries. The aim of the study is to describe the characteristics of paediatric death in hospitalised children and determine the predictors of death location in Hospital Universiti Sains Malaysia (USM). **Method:** Paediatric mortality cases for children aged between 29 days and 18 years old at the time of death were analyzed. These were documented cases between the year 2013 and 2020 at Hospital USM. Case notes were reviewed, and data were captured retrospectively. Multiple Logistic Regression was used to assess predictors of the location of death especially in the ward setting.**Results:** Out of 841 paediatric deaths identified during the period of the study, 544 cases were enrolled. The male gender has a higher proportion (1.4:1). The median age was 56 months, with infancy being the predominant age group. The median length of hospital stay was 10.5 days. More than half of the cases (58.3%) had underlying life-limiting illnesses. The majority of the patients had "Do Not Resuscitate" orders. A longer length of stay (prevalence odds ratio (POR 0.99, 95% CI 0.98, 0.99), being on ventilator (POR 3.42,95% CI 1.95, 6.01), being terminally ill (POR 0.40,95% CI 0.23, 0.70) and having underlying life limiting illness (POR 0.50, 95% CI 0.33, 0.75) were the significant predictors for the ward death. **Conclusion:** Understanding the characteristics of child death and the factors associated with death location is critical for improving paediatric care and treatment.
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INTRODUCTION

The published experience with child death audits is limited to a few countries, and some of these reports were retrospective descriptions of case mix and common causes of death rather than an evaluation of the death process itself. Even fewer reports are available on the factors influencing the location of death in the hospital setting.

The World Health Organization (WHO) defines Palliative Care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (1). The palliative care goal is to improve quality of life for both the patient and the family.

Khalid et al. reviewed the national hospital admissions database and found that majority of the terminal admissions were to the general ward (2). Nearly half (44.4%) of total deaths were of children with life-limiting illnesses and about one third (32%) of the remaining deaths were the non-neonatal age group with neoplasms. While majority of the terminal admissions were to the general wards, there were also children from the non-neonatal age group who died outside paediatric wards (14.2%). Dussel et al. found opportunity to plan location of death (LOD) was associated with high quality palliative care. In 63% of planned child's LOD and 97% had successfully accomplished their plan. Most studies gave a focus on LOD either at home, hospital or hospice setting.

Burns et al. found that patients who died beyond one week length-of-stay in the PICU were more likely to have pre-existing diagnoses, to be technology dependent prior to admission, and to have died following the withdrawal of life-sustaining treatment (3). Lago et al. evaluated the incidence of life support limitation and medical practices in the last 48 hours of life of children in Brazilian paediatric intensive care units (ICU) (4) found older age ($p = 0.025$) and longer PICU stay ($p = 0.001$) were associated with do-not-resuscitate (DNR) orders. The study found that even practicing with the DNR

orders, there were scarce initiatives for withdrawing or withholding life support measures. Despite having early preparation especially to children with life limiting illnesses (LLI), there are various factors which need consideration depending on the resources and support available locally. LLI is defined as an incurable condition that will shorten a person's life, though patients may continue to live active lives for years (2).

There is a scarcity of LOD information in Malaysia regarding factors that would have influenced on the paediatric patients' death. The local studies have looked at the demographic and clinical aspects of paediatric death without delving deeper into the predictors of death site (2,5,6). Previous studies compared LOD in the community versus in the hospital (7,8). However, this is not available in our local setting due to logistical, documentation and cultural issues. Comprehensive data on paediatric deaths could be easily collected for those who sought medical treatment in hospitals. Acutely ill patients are admitted to intensive care, and some with chronic illnesses would be managed in the general ward. Auditing the determinants on the location in paediatric patients' deaths at Hospital USM would be essential to address pertinent issues related to medical care in the future.

The goal of this study is to describe the characteristics of paediatric mortality cases, determine the overall mortality rate, and explore the factors associated with location of death, in the hospital setting.

MATERIALS AND METHODS

Study design

This was a retrospective medical records review of all paediatric deaths at Hospital Universiti Sains Malaysia (USM), Kelantan. Selected patients were in the age group of 29 days to 18 years old, with the time frame of the study from 2013 to 2020.

Study area and patients

Hospital USM is one of the major tertiary centre in the northeast of the Malaysian Peninsula. It has a 723 bed capacity and can handle a high volume of paediatric admission each year. The paediatric unit comprises of General Paediatric Ward, Paediatric Oncology Ward, and Neonatal Unit. There is a separate surgical ward. Because of the age diversity of paediatric patients, some adolescents with chronic medical disorders are frequently admitted to adult medical wards due to the lack of specific wards catering to this age group.

To study LOD, we divided 2 main areas of LOD, namely intensive care and ward. For neonate patients, Neonatal Intensive Care Unit (NICU) is the highest level of care for neonatal infants. In older patients, critical care is managed in the general adult ICU set up. The ward would include any wards outside ICU settings and the High Dependency Unit (HDU) which is reserved for either sick oncology or in-patient. Our HDU is not designated as a paediatrics ICU , and critically ill paediatrics patients would be prioritised and transferred to the adult ICU, due to lack of of paediatric intensivist personnel locally. All death cases in wards and HDU are considered as ward death.

The list of paediatric deaths from the age of 29 days to 18 years was obtained from the record office. Patients who were "brought in dead" or who failed resuscitation in the emergency department setting, were excluded from the study. Those who satisfied the inclusion criteria were taken as subjects, and their information was recorded in a standardized study pro-forma. A code number was assigned to each case in a systematic manner to ensure the confidentiality of the information. The cause of death and diagnosis at discharge were reviewed and classified according to International Statistical Classification of Disease 10 (ICD 10) and Related Health Problem. Further analysis was made according to standard definitions (Table I) to evaluate the determinants of the location of death in these patients.

Ethical approval

Ethical approval was obtained from the Human Research Ethics Committee (JEPeM-USM) with the approval code USM/JEPeM/21020163. Permission was also obtained from the Hospital Director prior to the commencement of the study. All information received was kept confidential and anonymous. No personally identifiable information was shared with the public.

Table I: Definition of cases

Brain death	formal determination of brain death in accord with institutional criteria
Withdrawal or withholding of medical treatment (WMMT)	Withholding treatment: not initiating or not increasing a life-sustaining intervention Withdrawal of treatment: discontinuing a life-sustaining intervention that was already in place in anticipation of death
Do Not Resuscitate Order (DNR Order)	A type of advance directive in which a person states that healthcare providers should not perform cardiopulmonary resuscitation (restarting the heart) if his or her heart or breathing stops.
Terminally ill	patient with disease that cannot be cured or adequately treated and is reasonably expected to result in death of the patient.
Sudden deterioration	rapid or unexpected deterioration while undergoing active treatments or investigations
Ventilator dependent	the failure to wean the patient from the ventilator while hospitalized in the intensive care unit or respiratory care center, in conjunction with continued use of a ventilator according to hospital discharge status
Parent wishes	documented wishes as per their preferences when they were given choices
Unexpected death	death which would not have been reasonably expected to occur 24 hours previously and in whom no pre-existing medical cause of death is apparent
Overall mortality rate	$\frac{\text{Total no. of paediatric death}}{\text{Total no. of paediatric admission}} \times 100$

Sample size

No sample size calculation was used. From 2013 to 2020, all eligible patients, aged 29 days to 18 years, at Hospital USM were included in the study. After using the exclusion criteria and considering untraceable case notes, we decided to include 544 patients in this study.

Data Collection

Data were collected and analysed for paediatric patients who died in the study time frame (2013-2020). The primary diagnosis of the child was classified as a life limiting illnesses which corresponds to the group described in Royal College of Paediatrics and Child Health cause of death (2). The source documents for retrieving information were the admission and mortality registers of the hospital during the period under review. Available case notes/folders were also retrieved. A proforma was used to obtain relevant information such as characteristics of study cases, causes of death and, characteristics of death according to location in the hospital setting.

Statistical analysis

Data was entered and analysed using Statistical Package for Social Sciences (SSPS) version 26. Descriptive statistics were calculated according to the patient's age, diagnosis, length of hospital stay, location of death, and DNR order. Pearson χ^2 tests were used to compare categorical variables. A Binary Logistic Regression model was used to investigate several explanatory variables to predict the location of death. Variables with a p-value of <0.25 and clinically significant variables from the univariate analysis were included. Multiple logistic regression was used to identify factors affecting the location of ward death. Statistical significance is considered if the p value is < 0.05.

RESULTS

During the study period, 33070 paediatric patients' between the ages of 29 days and 18 years old were admitted to Hospital USM. We discovered a total of 841 mortality cases in the same period. From these, only 544 cases were enrolled in this study.

Table II shows the characteristics of the study participants. Male gender has a slightly higher proportion (1.4:1) compared to the female. The median (IQR) age was 56 months (7.0-151.75) with infancy (29 days to 1 year old) being the predominant age group. The age group classification was based on Khalid et al (2). There were 40.4% of the study participants who died at the general ward (n=220), followed by 36% at the ICU (n=196), 15.6% at the NICU (n=85) and 7.9% at other wards (n=43) respectively. The median (IQR) length of hospital stay was 10.5 days (3.0-32.75). Of the study participants, 58.3% had underlying life-limiting illnesses.

Table II: Characteristics of the study participants

Variables	n (%)	Median (IQR)
Age, months		56 months (7.0-151.75)
29 days to 12 months	174 (32.0)	
13 months to 72 months	125 (23.0)	
73 months to 156 months	119 (21.9)	
157 months to 216 months	126 (23.2)	
Gender		
Female	228 (41.9)	
Male	316 (58.1)	
Location of death		
ICU	196 (36.0)	
NICU	85 (15.6)	
General ward/HDU	220 (40.4)	
Other wards**	43 (7.9)	
Length of hospital stay		10.5 days (3.0-32.75)
1-7 days	232 (42.6)	
8-30 days	167 (0.7)	
31-60 days	87 (16.0)	
> 61 days	58 (10.7)	
Life-limiting illness		
Yes	317 (58.3)	
No	227 (41.7)	
Diagnosis of death		
1) Cancer	66 (12.1)	
Leukemia/ lymphoma	14 (21.2)	
Brain/ central nervous system	38 (57.6)	
Sarcoma	4 (6.1)	
Osteosarcoma	2 (3.0)	
Others	8 (12.1)	
2) Non-cancer	478 (87.9)	
Congenital malformation/ chromosomal abnormality	27 (5.6)	
Cardiorespiratory disease	128 (26.8)	
Metabolic disease	10 (2.1)	
Neurodevelopmental disorder	26 (5.4)	
Others (including sepsis, abuse, injury)	287 (60.1)	

Intensive care Unit (ICU), Neonatal Intensive Care Unit (NICU), High Dependency Unit (HDU)
** Surgical, neurosurgical, plastic surgery, orthopedics

The proportion between cancer and non-cancer deaths with 87.9% due to non-cancer (n=478) and 12.1% due to cancer (n=66). Among non-cancer deaths, 60.1% (n=287) died due to acute causes such as sepsis or non-accidental or accidental injury, followed by 26.8% (n=128) from cardiorespiratory diseases, 5.4% (n=26) from neurodevelopment disorders, and 2.1% (n=10) from metabolic diseases. Participants who died due to cancer illnesses, 57.6%(n=38) were as a result of central nervous system malignancy, followed by 21.2% (n=14) from cumulative number of leukaemia and lymphoma cases.

Table III shows the characteristics of the patients for all the LOD. About two third of patients who died in the general ward and HDU had underlying LLI (76.8%). This pattern was not seen in the patients who died in the ICU, where more than half of them had non-cancer LLI (53.6%). Regardless of the location of death, the majority of the patients had a DNR order (general ward/ HDU 70.5%, ICU 81.6%, other wards 79.1%).

Table III: Characteristics of the patients by location of death

Variables	General ward/ HDU, 220 n (%)	ICU, 196 n (%)	Other wards, 43 n (%)
LLI			
Yes	169 (76.8)	84 (42.9)	18 (41.9)
No	51 (23.2)	112 (57.1)	25 (58.1)
LLI condition			
Cancer	86 (50.9)	39 (46.4)	13 (72.2)
Non-cancer	83 (49.1)	45 (53.6)	5 (27.8)
DNR order			
Yes	155 (70.5)	160 (81.6)	34 (79.1)
No	65 (29.5)	36 (18.4)	9 (20.9)
Mode of death			
Unsuccessful resuscitation	66 (30.0)	33 (16.8)	9 (20.9)
Brain death	3 (1.4)	37 (18.9)	3 (7.0)
Withdrawal/ withholding medical treatment	151 (68.6)	126 (64.3)	31 (72.1)

DNR -Do Not Resuscitation Order, LLI – Life limiting illness

Table IV: The annual and overall paediatric mortality rate for the year 2013 – 2020 for Hospital USM

Year	No. of admission per year	No. of death per year	Annual mortality rate (%)	Overall mortality rate (%)
2013	3428	140	4.1	**2.5**
2014	3752	160	4.3	
2015	4012	121	3.0	
2016	4505	59	1.3	
2017	4217	89	2.1	
2018	4527	74	1.6	
2019	4829	101	2.1	
2020	3800	97	2.6	
	Total = 33070	Total = 841		

In 2019, neonatal mortality rate for Malaysia was 4.6 deaths per 1,000 live births while under-five mortality rate for Malaysia was 8.6 deaths per 1,000 live births. [8].

Table IV shows the annual and overall paediatric mortality rate for 2013 – 2020. The overall mortality rate was 2.5%. The highest annual mortality rate was in the year 2014 (4.3%) while the lowest annual mortality rate was in the year 2016 (1.3%).

Table V shows predictors for the location of death among the study subjects. The multiple logistic regression analysis indicated that having a longer hospital stay ≥ 5 days (prevalence odds ratio (POR 0.99, 95% CI 0.98, 0.99), being on ventilator (POR 3.42,95% CI 1.95, 6.01), being terminally ill (POR 0.4,95% CI 0.23, 0.70) and having underlying LLI (POR 0.5, 95% CI 0.33, 0.75) were the significant predictors for the ward death among study subjects.

DISCUSSION

Malaysia was the home for 9.24 million children under the age of 18 years by the end of the year 2020, and about one third of the children (35.2%) were in Kelantan

Table V: Predictors for death among study subjects outside ICU

Variables	Simple logistic regression		Multiple logistic regression [a]	
	Crude OR (95% CI)	p-value	Adjusted OR (95% CI) [b]	p-value
Age				
< 5-year-old	1			
≥5-year-old	1.00 (0.99, 1.00)	0.91		
Sex				
Male	1	0.41		
Female	0.87 (0.62, 1.22)			
Duration of stay		<0.01		
< one week	1			
≥ one week	0.99 (0.98, 0.994=)		0.99 (0.98, 0.99)	<0.01
On ventilator		<0.01		
No	1			
Yes	5.26 (3.20, 8.67)		3.42 (1.95, 6.01)	<0.01
Terminally ill		<0.01		
No	1			
Yes	0.23 (0.14, 3.78)		0.40 (0.23, 0.70)	0.01
Family wishes		0.03		
No	1			
Yes	0.25 (0.10, 0.63)			
		0.03		
Sudden death				
No	1			
Yes	0.55 (0.32, 0.95)	<0.01		
Underlying life limiting illness				
No	1			
Yes	0.35 (0.25, 0.50)		0.50 (0.33, 0.75)	<0.01

[a] Backward logistic regression method was applied. Only variables that were included in the final model are presented in the table. Multicollinearity and interaction terms were checked and not found. Hosmer–Lemeshow test (p = 0.74) and classification table (overall correctly classified percentage = 68.8%), thus the fit of this model was achieved.

(9). Malaysia has achieved its target for under-5 mortality rate dropping to 6.51 deaths per thousand live births (in 2020) compared to 7.7 children per 1,000 live births in 2019 (10). Advances in medical knowledge, better child health services, improvements in child nutrition, and higher immunisation rates have all resulted in a dramatic drop in paediatric mortality.

Characteristics of the study participants

Our study showed that the male gender has a slightly higher proportion of death (1.4:1) compared to the female. This result is consistent with a study from 2017 (6). The median (IQR) age was 56 months (7.0-151.75) with infancy (29 days to 1 year old) being the predominant age group.

There was a slightly higher number of patients who died in the general ward (40.4%) as compared to the ICU (36%). In our setting, HDU has been classified as a general ward because its primary function is the care of oncological and in-patient emergency patients only. A significant number of 220 patients who died in the general ward, 75.9% (n=167) had perished in the HDU, indicating its importance as part of paediatric care at Hospital USM.

Nearly half of the patients had a 1-week (median 10.5 days) hospital stay and slightly more than half of them were known to have LLI. As the burden of care shifted towards home death in the modern world, hospitals in developing countries were still a place of care for children, with LLI leading to an increase in the hospital costs. Despite the fact that paediatric deaths can be sudden, acute or as a result of traumatic injuries, the median duration of hospital stay in this cohort was greater than or equivalent to one week. This is consistent with other findings (6). Such stays should have allowed these patients to receive end-of-life care, however, if offered, these were inadequately documented. This similar tendency has been observed in studies outside Malaysia (11,12).

Proportion between cancer and non-cancer deaths

Regardless of the underlying LLI, the cause of death was classified according to the ICD 10. The majority of the cause of deaths (87.9%) were caused by non-cancer causes, with acute event such as sepsis, abuse, and injury accounting for 60.1%.

Hospital USM is the pioneer for Paediatric Oncology in the northeast of the Malaysian Peninsula. The national data showed that the trend in oncology-related children's mortality was high. Most of these patients died due to an immunosuppressed state leading to overwhelming sepsis, as opposed to death from the malignancy itself. More than half of those who died from cancer, 57.8% died from brain tumours, and nearly a one fifth (21.2%) died from leukemia/lymphoma. Among the subjects with underlying leukaemia or lymphoma, 22.9% died due to disease progression. This was higher in children with primary brain tumuors (45.1%) and the finding is almost identical to the result by Dussel et al (8).

In adolescents, death was predominantly caused by injury. Trauma claimed the lives of more than half of the patients aged from 15 to18 years (54.4%). This is in line with the data published by the Centers for Disease Control and Prevention in 2019, which revealed that the major causes of death among teenagers aged 15–19 years were accidents (unintentional injuries), suicide, and homicide (13).

Characteristics of the patients who died in HDU

Out of 167 patients who died in HDU, about two-third of them had underlying LLI (74.3%), 70.1% agreed to a preliminary DNR order, and 68.3% died following the withdrawal or withholding of medical treatment. This is consistent with a previous study by Amy et al which found that about two-thirds of the study subjects had underlying LLI and nearly half of the study subjects had a DNR order in place at the time of death (14). Rebecca et al discovered that the most common cause of death was withdrawal or withholding of medical treatment (54.9%) despite the fact that the study only included patients who died in PICU (15). Of those who died following WMMT, eight patients were initially resuscitated, but the resuscitation was withheld at the parents' request.

Associations between the location of death with clinical characteristics

There were significant associations between the location of death (ward) and patients who were ventilator dependent ($p<0.01$), had sudden deterioration ($p=0.03$), were terminally ill ($p<0.01$), had parent's wishes ($p=0.002$) and had comorbidities ($p<0.01$).

Among ventilator-dependent patients, 41% of them died in the ward compared to 59% in the ICU ($p<0.01$). Over two thirds of the patients in the ward were those who were ventilated and succumbed in the non-gazetted HDU, which in our setting was part of the oncology ward. Other factors, such as the scarcity of ICU beds for paediatrics patients, which has resulted in ventilated patients being managed in a less than ideal ward setup. In ICU, 38.7% of those who had acute or sudden deterioration due to an acute event died, compared to only 68.3% on the ward ($p=0.03$). Although sudden episodes of deaths are rare in paediatrics, the spectrum of deaths in the general ward was difficult to predict unless the patients had underlying LLI.

In terminally ill patients, 24.3% of them died in the ICU compared to 75.5% in the ward ($p<0.01$). When compared to ICU, patients who were terminally ill were generally managed with supportive care in the ward. Our study findings revealed that the majority of these patients were supported in the general ward, rather than the ICU, until their demise.

Predictors for location of death

Longer duration of stay (prevalence odds ratio (POR) 0.99, 95% CI 0.98, 0.99), being terminally ill (POR 0.4,95% CI 0.23, 0.70), having an underlying LLI (POR 0.5, 95% CI 0.33, 0.75) and being on the ventilator (POR 3.42,95% CI 1.95, 6.01) were significant predictors of ward death among our patients in this study. It is also worth noting that being on a ventilator in the ward had 3.4 times higher risk of death than being in an ICU. This is consistent with the fact that patients with underlying LLI were terminally ill and stayed in the ward for a longer period of time. Those who died in the ward during the time period were less likely to be hospitalised for more than 5 days, have LLI and be terminally ill. We suspect all these cases were managed in the ICU setting.

Unpublished data from our center also showed that patients with co-morbidities had threefold higher risk of death, but the study did not address the potential clinical disparities related to the location of death (5). To the best of the author's knowledge, this is the first study in the country that has looked at the predictors related to the location of death among paediatric patients in the hospital set up. Previous studies have looked at the preferred versus actual place of death (16), and predictors of home death (5). Most of the studies were focused on the predictors of the location of interest whether it was their homes, hospices, or hospitals (17,18,19,20). Our study describes possible place of death in a hospital setting when there were no documented or recorded places of care preferences, resulting in the death in ICU despite the underlying LLI diagnosis.

We found 23.1% (n=51) of deaths occurred in the general ward. Most of non-LLI patients (57.1%) were admitted to the ICU for various reasons such as trauma, metabolic disease, or sepsis. There were also cases of congenital, neurodevelopment, cardiac and respiratory disease that could have contributed to the number of non-LLI in the ward. The department has implemented a monthly mortality review on the census to determine whether the mortality was appropriately managed and avoidable. We also have to acknowledge that resources for ICU access may be scarce, and these difficulties may delay transfer and optimization of care especially for the critical one.

Limitations

This study has several limitations. First, it represents the experience of a single university and tertiary centre that provides treatment to patients across Kelantan and neighbouring state particularly Terengganu. Second, in the presence of incomplete documentation, retrospective data extraction is intrinsically problematic. Although the amount of incomplete or missing data in this investigation was limited, we cannot be assured that missing data occurred at random. Third, our capacity to draw conclusions regarding timing or causality is limited by the retrospective cohort design. Rather, this research identifies relationships that should be investigated further in the future. Despite these limitations, this study is the first retrospective examination of how patient, illness, and treatment-specific characteristics may affect the place of death for children who died in this centre, and it paves the way for future research in this important and unexplored area. Future research is required to investigate individual characteristics that may influence palliative care service, such as investigating the home death option in a palliatively naïve population.

When it comes to preventable deaths in children under the age of 5, this is not studied in detail. However, the study has identified the needs to improve by having a designated area of intensive care for children. This would also include the availability of clinical and infrastructure support to ensure preventive measures can be achieved. The hospital must form a partnership with the community to ensure non-LLI cases receive treatment, so that death in this group is not only statistical number but treated appropriately. For LLI cases, improvement for home death could be improvised with appropriate planning and community support.

CONCLUSION

Understanding the characteristics of death in two different sites in a hospital would bring a better view on how to improve care for children with complex medical conditions. Several factors, including being ventilator-dependent, experiencing sudden deterioration, being terminally ill, fulfilling parent's wishes and having co-morbidities, are known to influence where the LOD in the hospital. The availability of palliative care services with appropriate community home support and a dedicated homecare service may change the preference of LOD for end-of-life care at home.

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