

Do children die? A retrospective review of deaths in a children's hospital

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INTRODUCTION We present a profile of deaths over two years in the medical departments of a children's hospital. The findings would help us better understand the individual dying experience of these patients. Service gaps and ways to optimise provision of supportive care were identified in the process.

METHODS The inpatient notes of all children who died in the medical wards, including intensive care unit, were traced and reviewed by the investigators. Demographic data, diagnoses, length of stay and the care received were recorded.

RESULTS A total of 68 children died in the two years. They were representative of all deaths nationally in terms of diagnoses. Two-thirds of the children died in the intensive care unit after having stayed there for an average of five days. All but one patient had invasive ventilation till they died. Eight out of every ten cases were assessed to be actively dying while being cared for. Most had 'Do-Not-Resuscitate' status in place, but few had been offered the option to choose the place of care or death when it became clear that they would not survive.

CONCLUSION More efforts could be made to improve the care of dying children and their families. The Paediatric Palliative Service could assist in advance care planning at the end of life.

Keywords: advance care planning, child, death, hospitals, palliative care
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INTRODUCTION

Despite advances in paediatric medical care, deaths among children in hospitals do occur. In a study by van der Wal et al from the Netherlands, 1%–2% of admissions in a tertiary children's hospital did not make it out of the hospital. 71% of these children died in the paediatric intensive care unit.⁽¹⁾ McCallum et al reported corresponding figures in Canada, where 83% of the children died in the intensive care setting, with 78% intubated prior to their death. 79% of patients had 'Do-Not-Resuscitate' (DNR) orders in their final admissions, but the median time from DNR order to death was less than one day. Acuity of care prior to death was described as very high.⁽²⁾

Death of a child is uncommon, and is widely perceived to be a catastrophic event. Not only do parents feel that they have failed to protect their child, clinicians and nurses working in the medical team struggle emotionally as well.^(3,4) No expense is spared to maximise all attempts to save any dying child, often delaying important decisions about end of life care to the very last moment. Part of the reason for this could also be the unease that medical professionals feel about sharing bad news. Brook and Hain reported that paediatricians "appear reluctant to document a diagnosis of dying, or discussions about resuscitation in the child's case notes until the last 24–48 hours of life".⁽⁵⁾

We aimed to profile paediatric medical deaths in our hospital, seeking to describe the numbers, the range of diagnoses and locations where they occurred. Another objective was to reflect the dying experience of these children by examining the care received before they died. In the process, we would discover

opportunities to better support the dying child and his/her family during this difficult time.

METHODS

This was a retrospective review of deaths that occurred in the Paediatric Medicine Department, including the Children's Intensive Care Unit (CICU), of KK Women's and Children's Hospital (KKH) in Singapore from 2008 to 2009. The sample was obtained from the death audit register routinely maintained and updated in CICU. The Statistics and Services Unit of the hospital provided backup data for corroboration. The inclusion criteria were both oncology and non-oncology diagnoses, deaths in the paediatric medical wards and CICU in 2008–2009 and death at birth to 19 years of age. The exclusion criteria were deaths from accident, poisoning and post surgery/procedures, still births, and deaths in surgical theatre/wards, emergency, neonatal departments or outside the hospitals, e.g. the patient's home.

The demographic data of children who died, their diagnoses and location of deaths within the hospital were obtained. The circumstances surrounding their deaths, e.g. whether they had been intubated and the length of time spent receiving intensive care, were also charted. Another parameter measured was the frequency of implementation of various degrees of advance care planning (ACP). When death was perceived to be 'inevitable' and 'imminent' by the medical team, we studied whether the family was given the opportunity to hear this and negotiate new goals of care. Incorporating the principles of care planning in children by Field and Behrman, we defined ACP in this context to include

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Table I. Demographic data of the patients.

Demographic	No. (%)
Age at death (mths)	
Median	59
Inter-quartile range	15–134
Absolute range	< 1–216
Gender	
Male	40 (59)
Female	28 (41)
Race	
Chinese	28 (41)
Others*	40 (59)
Nationality	
Singaporean	52 (77)
Others	16 (23)

* Including Indians and Malays.

three components.⁽⁶⁾ Firstly, there should be documented discussion with the family about the dire state of the child, followed by mutual negotiation of alternative care goals. Secondly, there should be formulation of a DNR order. Lastly, the individual family should be allowed to decide on the location of care (or place of death) in accordance with their wishes, since death was expected shortly. If any two of these three elements were fulfilled, ACP was coded as satisfactory. The referral rate to the in-house Paediatric Palliative Service (PPS) among oncology patients who had died was also evaluated.

Both the case files and electronic medical records of all the patients were analysed by the principal investigator (first author) for outcome data as described. The co-investigators verified the quality of data extraction by coding the medical folders that were randomly selected from the sample to compare. Continuous variables obtained were not found to be normally distributed. Therefore, inter-quartile ranges (IQRs) were reflected next to the medians in the results. Ethics approval had been obtained for this study.

RESULTS

A total of 68 children who met the inclusion criteria were studied. There were 38 paediatric medical deaths in 2008 and 30 deaths in 2009. The demographic characteristics of the patients are illustrated in Table I. The diagnoses were divided into categories in line with the classification used by our national death registry. The figures collected over the two years were tabulated and their relative frequencies compared with figures at the national level in order to highlight the close similarity in prevalence of specific conditions (Table II).

Before their deaths, the children would have lived with their underlying conditions for a median of 12 (IQR 1–39) months. 44 out of 68 (65%) children died in intensive care. From this group, all except one child had been intubated and received invasive ventilation (63%). Based on the patients' last hospitalisation, we evaluated the length of stay, the duration of stay in the CICU and duration of invasive ventilation (if any) before death (Table III).

At some points during their admissions, eight out of ten children were not expected to survive. From the attending

Table II. Incidence of deaths classified by diagnosis.

Diagnosis	No. of deaths		
	KKH		National*
	2008	2009	2008 ⁽⁷⁾
Cancers	10	10	36
Congenital anomalies	9	5	46
Infections	8	4	29
Cardiovascular diseases	3	4	10
Perinatal conditions	3	3	39
Cerebrovascular diseases	0	2	3
Other medical conditions	5	2	30

*Patients aged 0–19 years.

Table III. Length of hospital stay and duration of invasive ventilation.

Type of care	Median; IQR (days)
LOS for terminal admission (n = 68)	6.5; 2–23
LOS in ICU (n = 44)	5; 1–20
Duration of invasive ventilation (n = 43)	3; 1–19

LOS: length of stay; IQR: interquartile range; ICU: intensive care unit

physicians' perspectives, 54 out of 68 (79%) patients (poor prognoses) were perceived to be actively dying while under their care. This information was obtained indirectly from entries in the clinical notes. Within this subset of patients, we examined the rates of DNR orders and degree of ACP, as defined earlier, and found that 48 out of 54 (89%) children had DNR orders when their prognoses were deemed to be poor. ACP was documented in 38 out of 54 (70%) patients with decidedly dismal outcomes. The utilisation of the PPS among oncology patients was examined. Out of the 21 patients with cancer, 11 (52%) were referred to the team for symptom and supportive care before they died. Incidentally, four of the children with non-oncology conditions were co-managed between the PPS and primary physicians. We also evaluated whether children with cancer were still on chemotherapy with curative intent 48 hours before their demise. We identified four such children; all had unexpected sudden deterioration. Two had acute myelocytic leukaemia, one died from intracranial haemorrhage and the other, from hyperleukostasis syndrome. The remaining two oncology patients had acute lymphocytic leukaemia (one was in remission and the other had a relapse) complicated by H1N1 influenza infection just before they died. Both succumbed to overwhelming sepsis.

DISCUSSION

There are limited studies on mortality in paediatric hospitals in general, and hardly any local reports. The comparatively smaller number of paediatric mortalities, as compared to that of the adult medical population, may be the reason for the paucity of studies. Out of a total of 39,900 admissions into our Paediatric Medicine Department in the two years of this study, there were 92 deaths in total (0.23% of admissions), excluding stillborns. We studied a subset of 68 deaths in detail.

Comparing with the latest death statistics from the Registry of Births and Deaths Singapore 2008 for causes of deaths (excluding accidents and trauma), our figures are fairly representative.⁽⁷⁾ The most common diagnosis was cancer in our cohort, whereas it was ranked third on the national census. This is likely due to our study's exclusion of stillbirths and deaths that occurred in the neonatal department. Neonates who are very ill come under the care of the neonatology team after delivery in KKH, unless they are discharged and then re-admitted to our Paediatric Medicine Department. Apart from congenital anomalies and perinatal conditions, the other categories were all consistent in level of prevalence in our study.

Our figures for location of deaths within the hospital were unexpected. A significant number (more than a third) of deaths in our study occurred outside of intensive care. On closer examination of the data, two main reasons could be elicited. Some of these patients had advanced pre-existing conditions, and their parents had agreed with the medical team to not escalate treatment beyond the ward level when the condition deteriorated. At KKH, patients with conditions of intermediate severity may be managed in the high-dependency ward with close monitoring or non-invasive ventilation, instead of the CICU. The patients who died outside intensive care in our cohort either had limits set to their treatment or deteriorated rapidly within this environment.

In our study, there was a mix of both oncology and non-oncology cases among the mortalities. Despite the varied trajectories, the majority (around 80%) of deaths were anticipated. Nine out of ten of these cases had a DNR order in place, which was pivotal. Ethically, any further resuscitative efforts at this point would have been clearly futile and possibly harmful. Ensuring accurate communication at handover is imperative in a busy hospital with change of teams around the clock. The orders were mostly documented in the continuation notes within the medical folder. A drawback of this practice is that it may not get flagged if the child acutely deteriorates. One patient, in fact, had cardiac massage inadvertently performed despite a DNR order.

The benefits of ACP to young patients and their families have been reported.⁽⁸⁾ Seven out of ten families in our study had documentation of the breaking of bad news and discussion of further management options (two of the three components of ACP) when the child was assessed to be actively dying. This is commendable, but more could be done. Rarely was the option of dying at home offered despite this being the choice most families would want.⁽⁹⁾ This is obviously dependent on the particular clinical context and the available resources, e.g. PPS and supporting community services.

Only half of our children with cancers received support from the PPS. Among those who received palliative care, it would be beneficial to know when they were referred in future audits. In Taiwan, a retrospective cohort study involving 1,208 paediatric cancer decedents reported that palliative care was

provided to only 7.2%, and 21.8% of these were referred only within the last three days of life.⁽¹⁰⁾ Anecdotally, the PPS is often involved 'too little too late'. By the nature of the illness and the potential risks the young patient is subjected to during aggressive treatments, the authors believe that the PPS could make a significant contribution to the wellbeing of the child and the family throughout his/her disease trajectory. A recent report has shown beneficial survival outcomes of early involvement of the palliative care team in the management of metastatic cancer in adults.⁽¹¹⁾ Palliative teams have also been involved in helping primary teams and their patients with terminal extubations and rapid discharges home to die, both in cancer and non-cancer conditions.

The limitations of this study include bias due to incomplete documentation, particularly in regard to the attending physicians' perception of poor prognoses while the patients were still under active care. Important discussions that occurred at the bedside might not be evident in the medical notes. This is not universal, but quality is indeed inconsistent. Causes of death were sometimes the same as the primary diagnoses while direct precipitants of death were stated at other times. When documented, the causes of death were predominantly infections, and to a lesser extent, bleeding, especially among the oncology cases. Among the outliers, one child had status epilepticus and another, acute renal failure. Some of the patients had multiple morbidities, while others had only presumptive diagnoses, especially among those with neurological conditions. In addition, we were unable to comment on the lived experience of the dying child or the family in terms of the suffering and unmet needs. Future research could focus on an in-depth exploration of the local experience of parents surrounding care at the terminal phase.

As this was a single-centre study, the findings reported here do not reflect the prevailing patterns of disease and standard clinical practice in all paediatric hospitals in Singapore. We have defined the nature and size of the problem. Medical teams should begin to recognise the need to realign care goals in tandem with the changing conditions of their patients. ACP is certainly recommended when a child's clinical status worsens. It has implications in resource allocation (e.g. CICU bed utilisation) and service delivery (e.g. inappropriate calls for code). By actively providing information and options, we demonstrate a respect for autonomy and acknowledge the tremendous pain in the potential loss of a child. As Dussel et al reported, "*The opportunity to plan location of death may be a better proxy for high quality end of life care than the actual location of death*".⁽¹²⁾ For challenging situations in which families struggle with difficult decisions, PPS can help. Feudtner et al, in their study of deaths occurring in 60 children's hospitals in the United States, posed the following scenario. "*Given the high proportion of all fatal cases that were mechanically ventilated, issues of limiting and withdrawing care will perform be one of the challenges that palliative care teams will confront*".⁽¹³⁾ The PPS can assist

in ACP in partnership with the primary team. All parties can benefit from the service's intimate knowledge of resources in the community for continuation of care, especially if a rapid terminal discharge is contemplated. In fact, care does not terminate when the child dies. Bereavement care is a major remit of the PPS, in addition to other tasks like supporting surviving siblings and grandparents as they begin to grieve the loss of a family member.

In conclusion, despite aggressive management, deaths among children could occur due to various medical conditions. Some may be sudden, but the majority are expected. These children have often exhausted all therapeutic options after very aggressive treatment. In our centre, we have provided ACP to a certain extent, but more could be done. The PPS could certainly provide their expert input outside the traditional adult model of cancer supportive care, by collaborating with other specialists within the children's hospital. We owe it to our young patients to do the best we can, even when everything else fails.

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