

3RD ICPCN CONFERENCE 2018

PAEDIATRIC PALLIATIVE CARE: ARE WE DOING ENOUGH?

A Retrospective Review of Paediatric Deaths
over 5 years in an Academic Tertiary Hospital

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Introduction

- Despite advances in paediatric medical care, deaths among children in hospitals still occur.
- Decision making at the end of life for infants and children is among the most difficult experiences families will ever encounter.
- This is among the most important and profound professional responsibilities for the clinicians who care for them.

Introduction

- Paediatric palliative care is a relatively new and under-studied subspecialty in Singapore and there are limited studies on the epidemiology of paediatric mortality.
- Chong et al¹ presented a retrospective review of deaths that occurred over a 2 year duration, highlighting that more could be done to improve the care of dying children, such as engagement of paediatric palliative care services to assist in advance care planning.

¹ Chong PH, Chan MY, Mohamad LI. Do children die? A retrospective review of deaths in a children's hospital. Singapore Med J 2012; 3:192-5.

Introduction

Our institution

- Tertiary academic center
- 4 paediatric wards, 90 inpatient beds
- National solid organ transplant programme (liver, renal transplants)
- Bone marrow transplants
- Complex congenital cardiac surgery

Introduction

- Paediatric palliative inpatient service
 - 1 palliative care consultant (trained in adult palliative care)
- STAR PALS
 - Home palliative care service started in 2012

Aims

- To study the **epidemiology of paediatric deaths** in the department of paediatrics over a duration of 5 years
- To evaluate palliative and end-of-life care provided to these patients

Methods

- Retrospective study
- The medical records of all patients who died in the paediatric wards and the paediatric intensive care unit, from 2012 to 2016, were reviewed.
- The following information were obtained:
 - Demographic data
 - Past medical history
 - Cause of death
 - Referral to palliative care services
 - Use of life-sustaining therapies



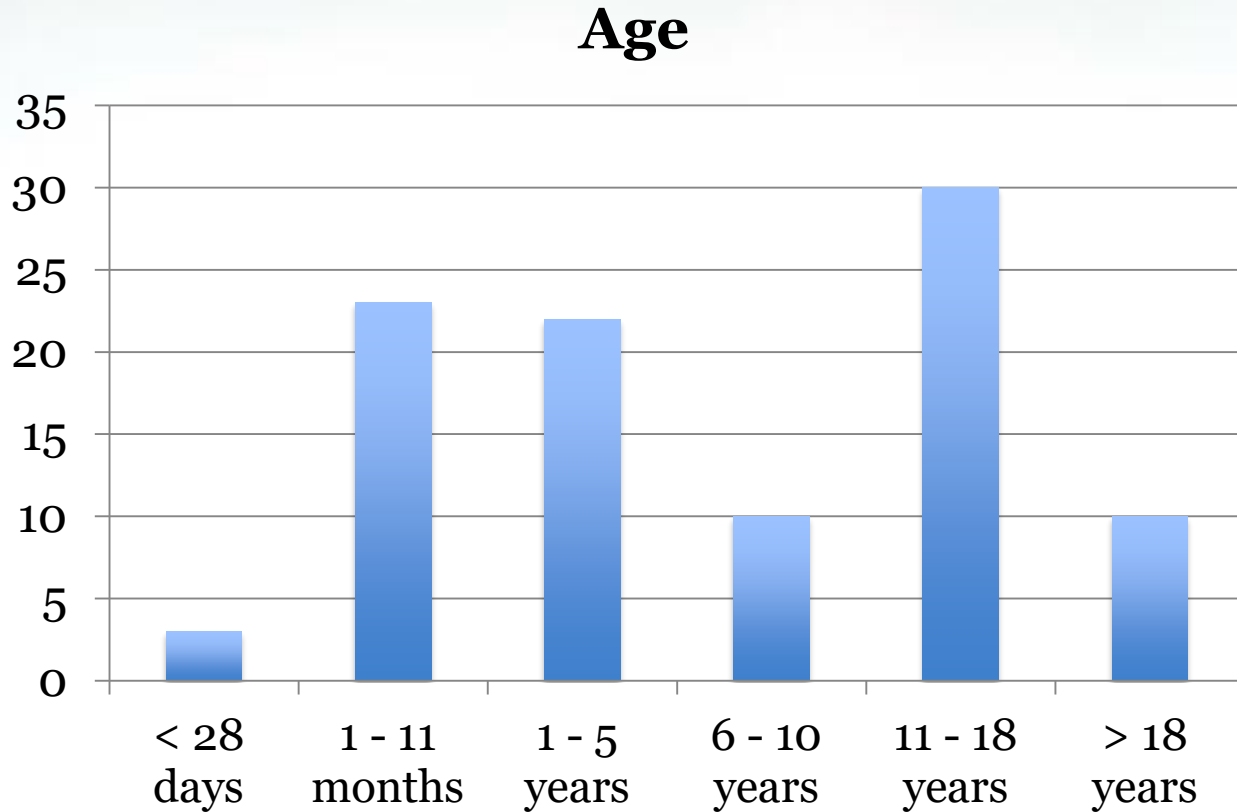
Results

Results

A total of **98 patients** died in the 5 years and the average mortality rate was 0.34%.

$$\begin{aligned} & (\text{Number of deaths} / \text{Total inpatient admissions}) \times 100 \\ & = 98 / 28516 \times 100 = 0.34\% \end{aligned}$$

Patient Demographics

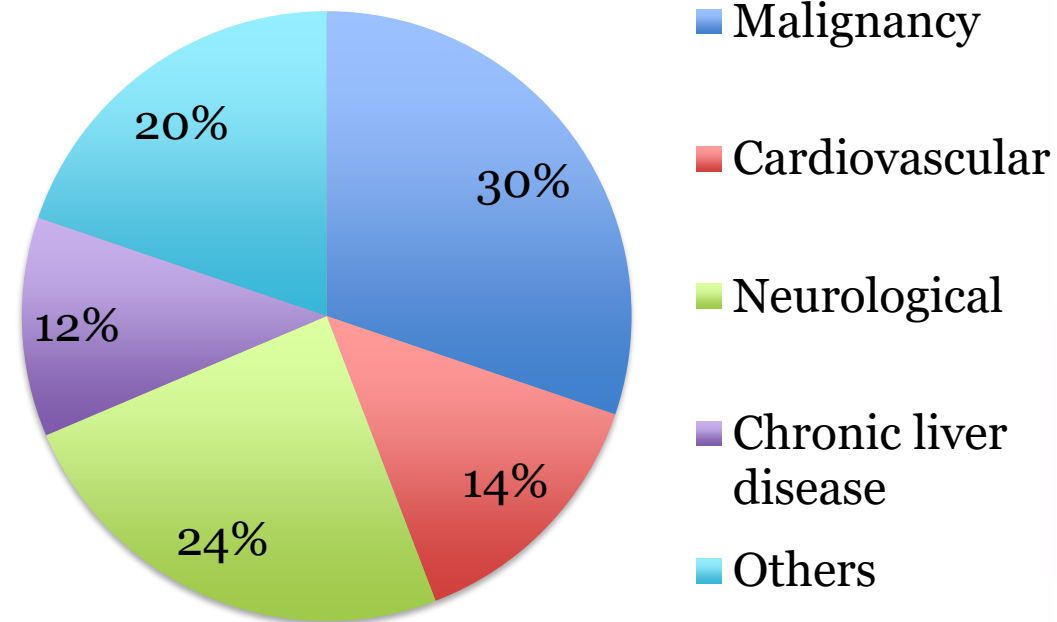


Most deaths occurred in children aged 11 to 18 years old (31%), with a median age of 6.

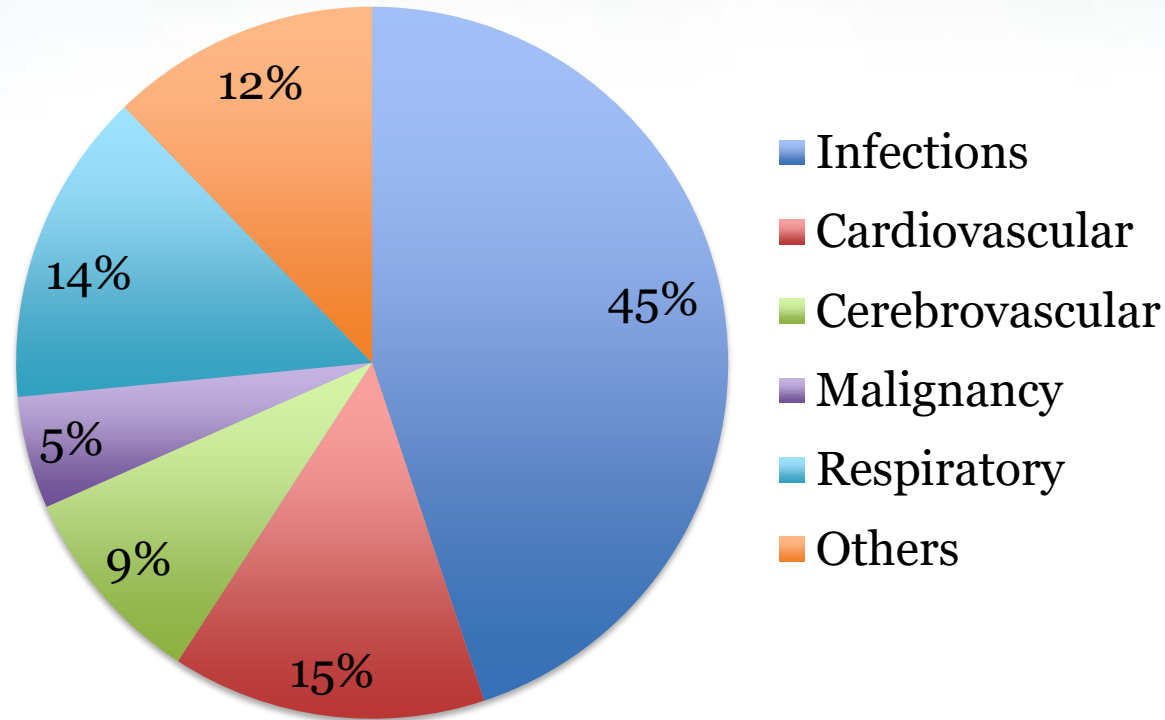
Patient Demographics

Demographics	No. (%)
Gender	
Male	60 (61)
Female	38 (39)
Race	
Chinese	47 (48)
Malay	22 (22)
Indian	6 (6)
Others	23 (24)
Nationality	
Singaporean	69 (70)
Foreigner	29 (30)
Past Medical History	
Yes	86 (88)
No	12 (12)

Past Medical History



Cause of death

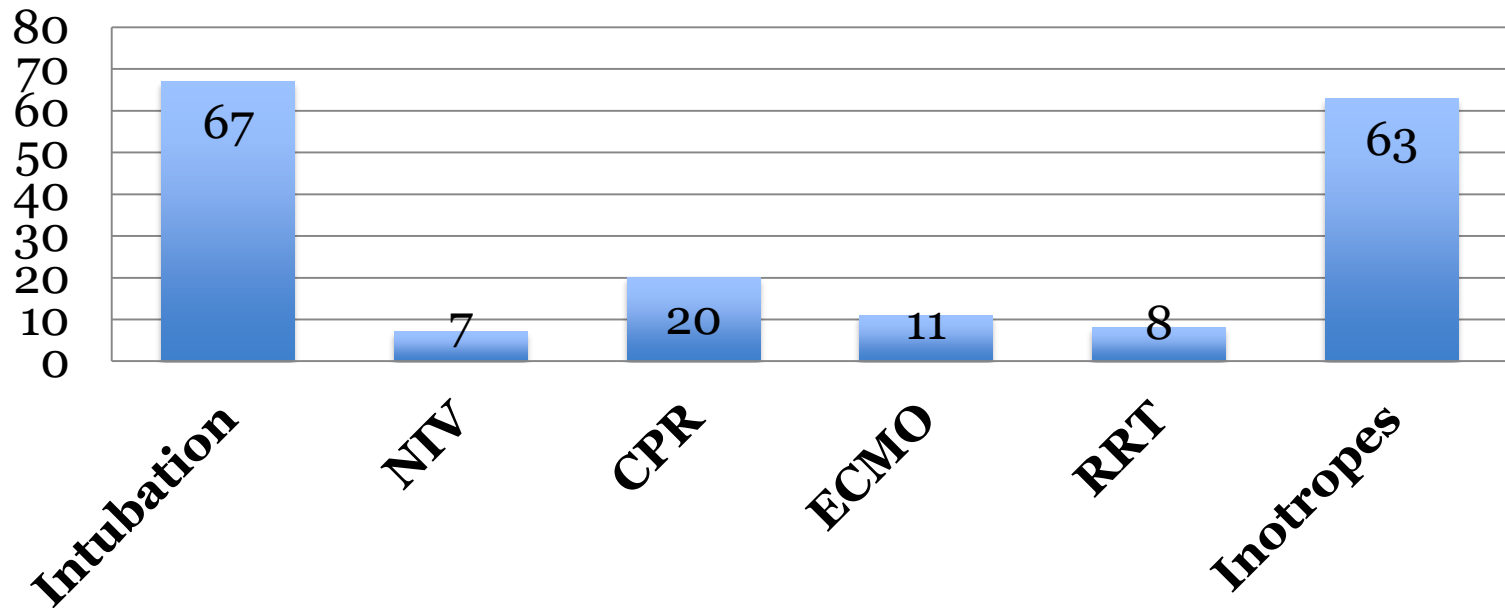


- Majority of deaths (45%) were due to infections, of which the most common causes were that of pneumonia and sepsis.
- 93 (95%) of deaths were expected.

Life sustaining intervention

87 patients (89%) were admitted to the ICU. The duration of ICU stay ranged from 1 to 146 days, with a median of 9 days.

Life sustaining measures during the last 24hrs before death



NIV – Non invasive ventilation

ECMO – Extra corporeal membrane oxygenation

CPR – Cardiopulmonary resuscitation

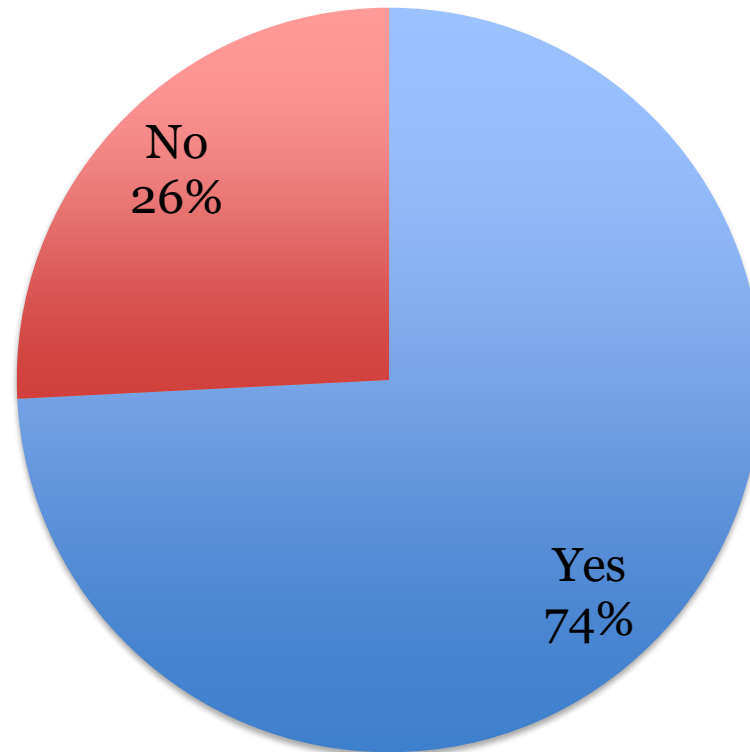
RRT – Renal replacement therapy

Circumstances surrounding death

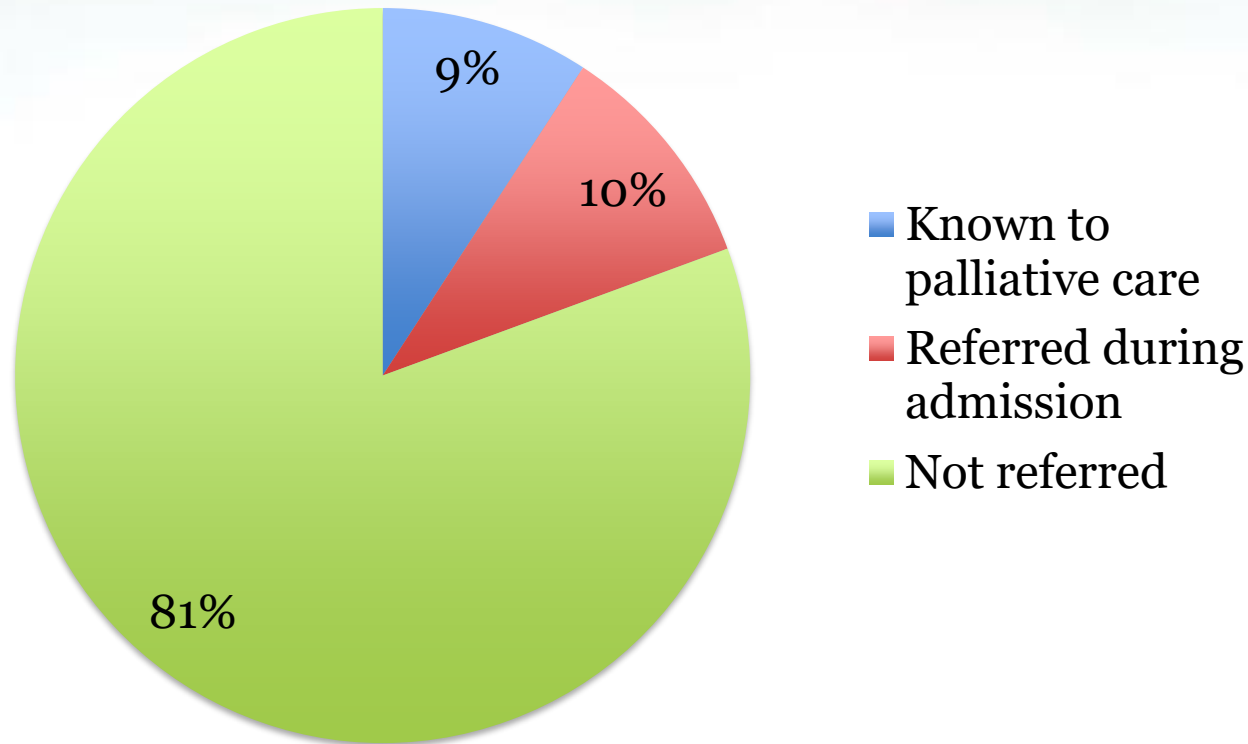
Circumstances	No. (%)
Nature of death	
Withhold / Withdrawal of life-sustaining treatment	78 (80)
Failed CPR	17 (17)
Brain death	3 (3)
Place of death	
ICU	81 (83)
General Ward	15 (15)
Others (Operating Theatre)	2 (2)

Comfort care

Analgesia provided in the last 24hrs before death (in those whom death was expected)



Palliative care referrals



The number of days from palliative care referral to death ranged from 2 to 16 days, with a mean of 6.6 days.

End-of-Life decision making

- In all of the cases in whom death was expected, there were documented discussions with family regarding goals of care during the course of illness.
- 5 of the 9 cases (55%) known to palliative care service had documented advanced care plans.



Discussion

Discussion

- Although majority of paediatric patients who died had pre-existing life-limiting conditions, very few were referred to palliative care. Those who were referred were referred at end of life.
- Possible reasons for this include:
 - Stigma associated with palliative care in the Asian context
 - Lack of understanding of families and physicians, as to what palliative care service provides
 - Lack of resources / expertise

Discussion

- Limitations of the study
 - Missing information from incomplete documentation
 - Information obtained largely quantitative, unable to comment on the personal experiences of patients and families
 - Single center study – may not be representative of the whole population

Discussion

- Future research / development
 - Looking into perceptions of healthcare staff, patients and families to pediatric palliative care
 - A more in depth exploration of the personal experience of patients and their families
 - Expanding the paediatric care service

Conclusion

- By profiling paediatric deaths in our institution, this study gives us a **greater insight into the needs and potential challenges** in managing this special group of patients
- More can be done to improve their care, such as **early referral to palliative care, establishment of advanced care plans, and providing adequate analgesia** when death is imminent.

References

1. Chong PH, Chan MY, Mohamad LI. Do children die? A retrospective review of deaths in a children's hospital. *Singapore Med J* 2012; 3:192-5.
2. Burns, Jeffrey P. et al. Epidemiology of Death in the Pediatric Intensive Care Unit at Five U.S. Teaching Hospitals. *Critical care medicine* 42.9 (2014): 2101–2108. *PMC*. Web. 27 June 2017.
3. Phua J, Kee AC, Tan A, . End-of-life care in the general wards of a Singaporean hospital: an Asian perspective. *J Palliat Med* 2011; 14: 1296–1301.

Thank you

