Beyond Mortality: Assessing Pediatric Palliative Care Needs

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Background
Pediatric palliative care is an interdisciplinary service that works to enhance the quality of life for children with serious illness.

Need for palliative care is often determined by mortality data and the incidence of complex chronic conditions (CCC) at the time of death:
• 27-60% of patients have a CCC at the time of death
• 21% of deaths are directly attributable to a CCC

Aims: Characterize the palliative care needs of an inpatient pediatric population prior to mortality, which we hypothesize will be substantial.

Results
273 questionnaires were completed over 3 weeks.

45% of patients met at least one palliative care referral criterion (n=122).

Proportion of positive screens varied by location of admission (Fig. 2).

Most patients with a positive screen (74%, n=90) had a serious illness (Fig. 3):
• 70% met additional palliative care referral criteria (n=63)
• 21% with a serious, life-limiting diagnosis met all four criteria (n=19, Fig. 4)

Poor symptom control was reported in 55% of patients with a positive screen (Fig. 3).
• This comprised 25% of all patients surveyed (67/273)
• Some of whom did not have a serious, life-limiting diagnosis

Figure 2. Pediatric Palliative Care Survey: Assessing Need (N=273)

Surveys were scored as positive when any of the first four criteria were selected. Surveys were negative when the fifth (null) criteria was selected. General and subspecialty patients were combined because they were admitted to the same pediatric units. Overall, 45% of surveys screened positive.

Figure 3. Prevalence of Individual Criterion among Screen-Positive Surveys (n=122)

Error bars represent standard error of the mean. 76 surveys had more than one criteria selected (62%).

Conclusion
This study used morbidity, instead of mortality, to identify the considerable need (45%) for palliative care among pediatric inpatients at a tertiary care children’s hospital.

Additionally, 25% of pediatric inpatients were noted to suffer from poor symptom control, indicating a specific focus for palliative care consultation.

The unit-specific data clarified where palliative care services are most urgently needed within the hospital, and can be used to direct distribution of palliative resources.

Future Directions
• Differentiate the need among general and subspecialty pediatric patients
• Study neonatal intensive care patients and their distinct palliative care needs

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References
Freibert, S and Osenga, K. Pediatric Palliative Care Referral Criteria. Center to Advance Palliative Care. 2009

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Figure 4. Magnitude of Palliative Needs of Screen-Positive Patients with a Serious, Life-Limiting Diagnosis (SLLDx) (n=90)

90 patients met the criteria of serious, life-limiting diagnosis. 70% met one or more additional criteria (n=63).

The palliative care criteria were 1) serious, life-limiting diagnosis, 2) frequent admissions and escalating care requirement, 3) persistent, poor symptom control, and 4) a need to clarify the goals of care.