

# 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

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

## Design

A cross-sectional survey was performed using an adapted pediatric palliative care referral tool (See Figure 1).

## Setting and Participants

During one month in Fall 2015, senior pediatric residents completed the survey for patients upon admission to the:

- Pediatric intensive care unit
- Hematology, oncology, and bone marrow transplant unit
- Medical units, under a generalist or subspecialist

Non-PICU surgical patients and neonatal intensive care unit patients excluded

## Figure 1. Pediatric Palliative Care Survey

Team \_\_\_\_\_

**Yale-New Haven Children's Hospital - Palliative Care Needs Assessment**

Please fill out an assessment for every patient within 24 hours of admission. This information will be used solely for data collection and will not trigger a referral to palliative care services. For questions, please contact Tanya Murtha at [tanya.murtha@yale.edu](mailto:tanya.murtha@yale.edu). This form is intended to be completed by the senior resident. Thank you!

PLEASE CHECK ANY AND ALL CRITERIA THAT APPLY TO YOUR PATIENT	✓
1. SERIOUS, LIFE-LIMITING DIAGNOSIS* <i>Relapsed or progressive metastatic cancer, advanced cystic fibrosis, chronic ventilation, progressive genetic or metabolic syndrome, neurodegenerative disease, severe immunodeficiency, single ventricle physiology, etc.</i>	
2. FREQUENT ADMISSIONS AND ESCALATING REQUIREMENTS FOR MEDICAL CARE <i>≥ 3 admissions in the past 6 months OR hospital admission ≥ 3 weeks duration OR ≥ 5 days of mechanical ventilation</i>	
3. PERSISTENT, POOR SYMPTOM CONTROL <i>Uncontrolled pain, nausea/vomiting, dyspnea, constipation, seizures not due to an acute cause OR permanent/prolonged change in functional status</i>	
4. GOALS OF CARE NEEDED IN PATIENT WITH CHRONIC ILLNESS <i>Conflict regarding treatment plan OR patient/family needs assistance with goals of care OR poor prognosis with no plan of care established OR unrealistic goals of care or expectations for recovery</i>	
5. NONE OF THE ABOVE APPLY	

\*See expanded list of serious, life-limiting diagnoses below (broken down by system)

<b>Cardiac Criteria:</b> <ul style="list-style-type: none"> <li>• Complex congenital heart disease, especially single ventricle cardiac physiology, severe pulmonary hypertension, Ebstein's anomaly, Eisenmenger's syndrome, and pulmonary atresia</li> <li>• Cardiomyopathy and severe myocarditis</li> <li>• Ongoing discussion of cardiac transplant</li> <li>• Cardiac diagnosis with underlying neurological/chromosomal diagnosis</li> <li>• ECMO candidate</li> <li>• Cardiac arrest with prolonged down time</li> </ul>	<b>Gastrointestinal Criteria:</b> <ul style="list-style-type: none"> <li>• Multi-visceral organ transplant under consideration</li> <li>• Biliary atresia, progressive hepatic or uremic encephalopathy</li> <li>• Total aganglionosis of colon, long-segment Hirschsprung's</li> <li>• Feeding tube under consideration for any neurological condition</li> <li>• Patients who are chronically ventilator intolerant</li> </ul>	<b>Neurologic/Neuromuscular/Neurodegenerative Criteria:</b> <ul style="list-style-type: none"> <li>• Progressive neurodegenerative conditions</li> <li>• Muscular Dystrophy/Spinal Muscular Atrophy</li> <li>• Severe Traumatic Brain Injury, Persistent Vegetative State, severe anoxic brain injury</li> <li>• Brain reduction syndromes, static encephalopathy</li> <li>• MRCP with comorbidities</li> </ul>
<b>Intensive Care Criteria:</b> <ul style="list-style-type: none"> <li>• Prolonged or failed attempt to wean mechanical ventilation</li> <li>• Multi-organ system failure</li> <li>• Compassionate extubation</li> <li>• PICU stay longer than two weeks</li> <li>• Irreversible brain injury that will impact functional status</li> <li>• Immersion injury</li> </ul>	<b>Pulmonary Criteria:</b> <ul style="list-style-type: none"> <li>• Patients with CF considering lung transplant, with FEV1 &lt;30%, vent dependence, or ineligible for lung transplant</li> <li>• Bronchiolitis obliterans</li> <li>• Central hypoventilation syndromes</li> <li>• Patients who are chronically ventilator dependent</li> </ul>	<b>Infectious Disease Criteria:</b> <ul style="list-style-type: none"> <li>• HIV/AIDS resistant to antiretrovirals</li> <li>• Severe Combined Immune Deficiency and other severe immunodeficiency syndromes</li> <li>• Congenital CMV/Toxo with neurological sequelae</li> <li>• Severe encephalitis</li> </ul>
<b>Metabolic/Inclusion Disease Criteria:</b> <ul style="list-style-type: none"> <li>• Krabbe's, Hunter's / Hunter's, Niemann-Pick, Menke's, Pompe, Tay Sachs, Fabry's, Sandof's diseases and Sanfilippo syndrome</li> <li>• Severe mitochondrial disorder</li> <li>• Severe metabolic disorders</li> </ul>	<b>Genetic Criteria:</b> <ul style="list-style-type: none"> <li>• Trisomy 18, 21, 15, severe forms of osteogenesis imperfecta (type 3 or 4), Potter Syndrome, Rett's Syndrome</li> <li>• Chromosomal anomalies with known poor neurologic prognosis</li> </ul>	<b>Malignant Disease Criteria:</b> <ul style="list-style-type: none"> <li>• Progressive metastatic cancer</li> <li>• Bone marrow/stem cell transplant</li> <li>• Any newly diagnosed malignant disease with an EFS of &lt;10%</li> <li>• Any relapsed malignant disease</li> </ul>
<b>Neonatal Criteria:</b> <ul style="list-style-type: none"> <li>• Extreme prematurity with concomitant severe BPD, IVH, PVL, etc. or VLBW infants</li> <li>• Severe birth asphyxia, hypoxic ischemic encephalopathy</li> </ul>	<b>Renal Criteria:</b> <ul style="list-style-type: none"> <li>• Neonatal polycystic kidney disease</li> <li>• Renal failure, not transplant candidate</li> </ul>	<b>Orthopedic Criteria:</b> <ul style="list-style-type: none"> <li>• Severe progressive scoliosis</li> <li>• Severe forms of dwarfism</li> </ul>

## 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).

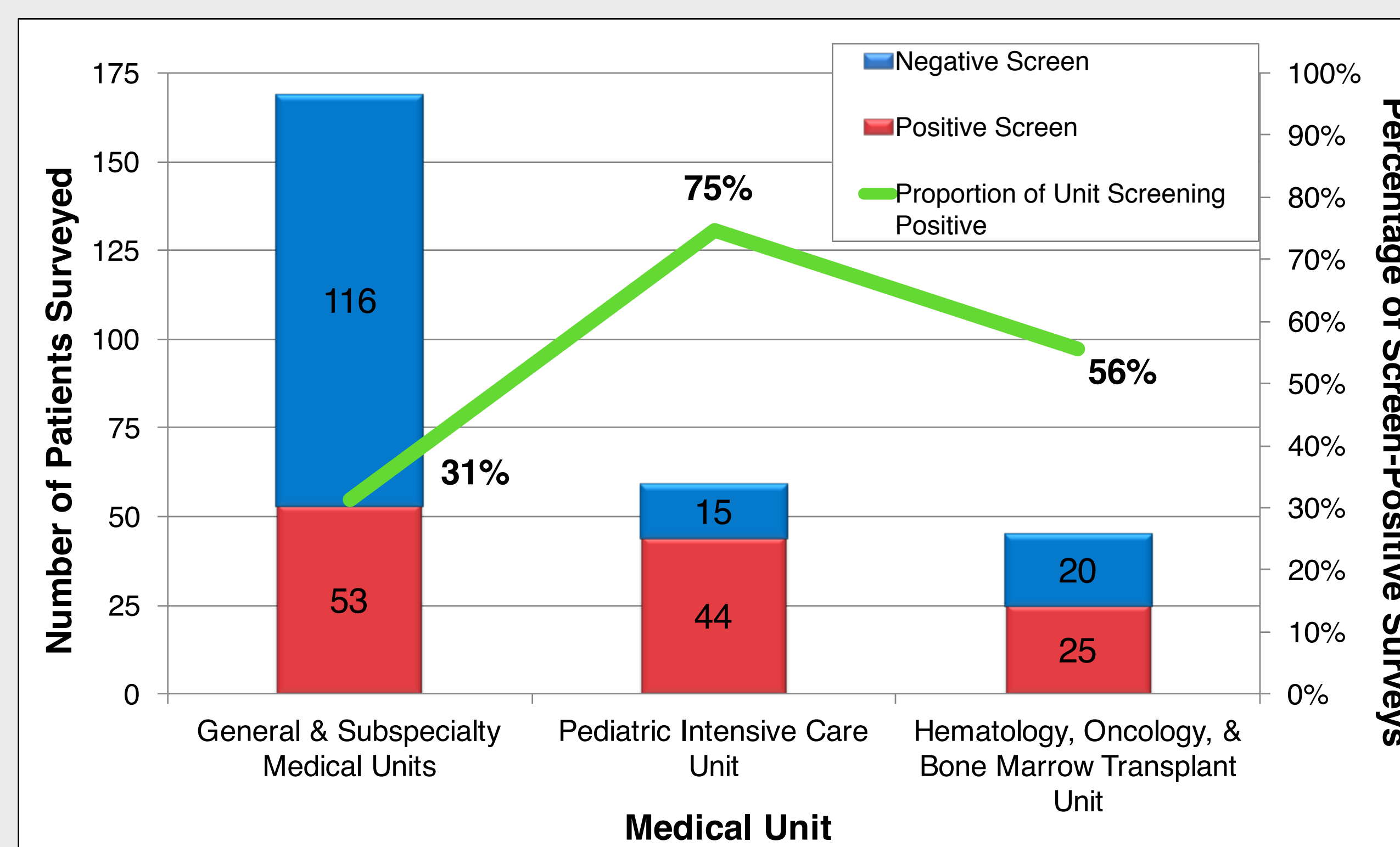
Most patients with a positive screen (74%, n = 90) had a serious illness (Fig. 3).

- 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).**

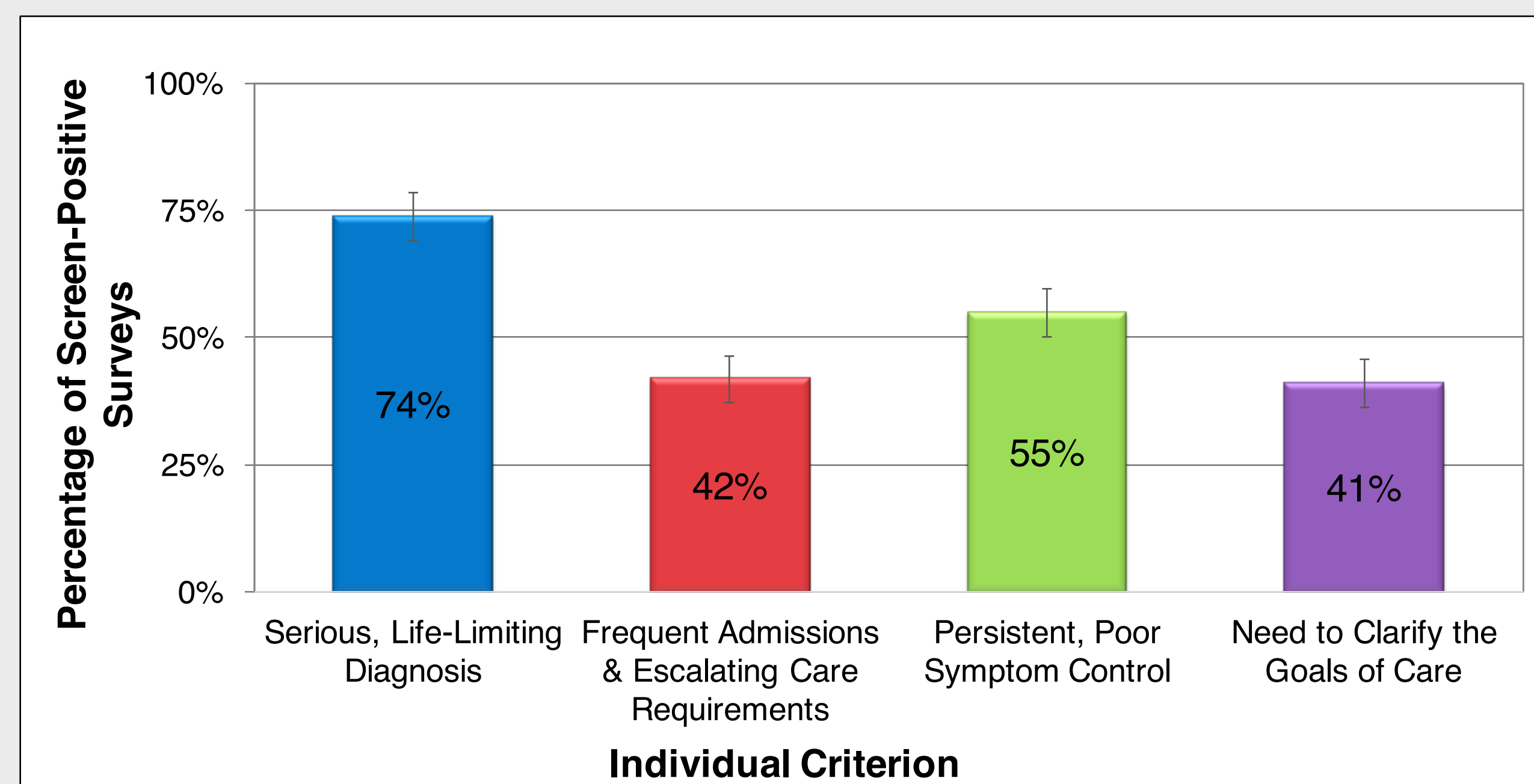
- This comprised 25% of all patients surveyed (67/273)
- Some of whom did *not* have a serious, life-limiting diagnosis

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



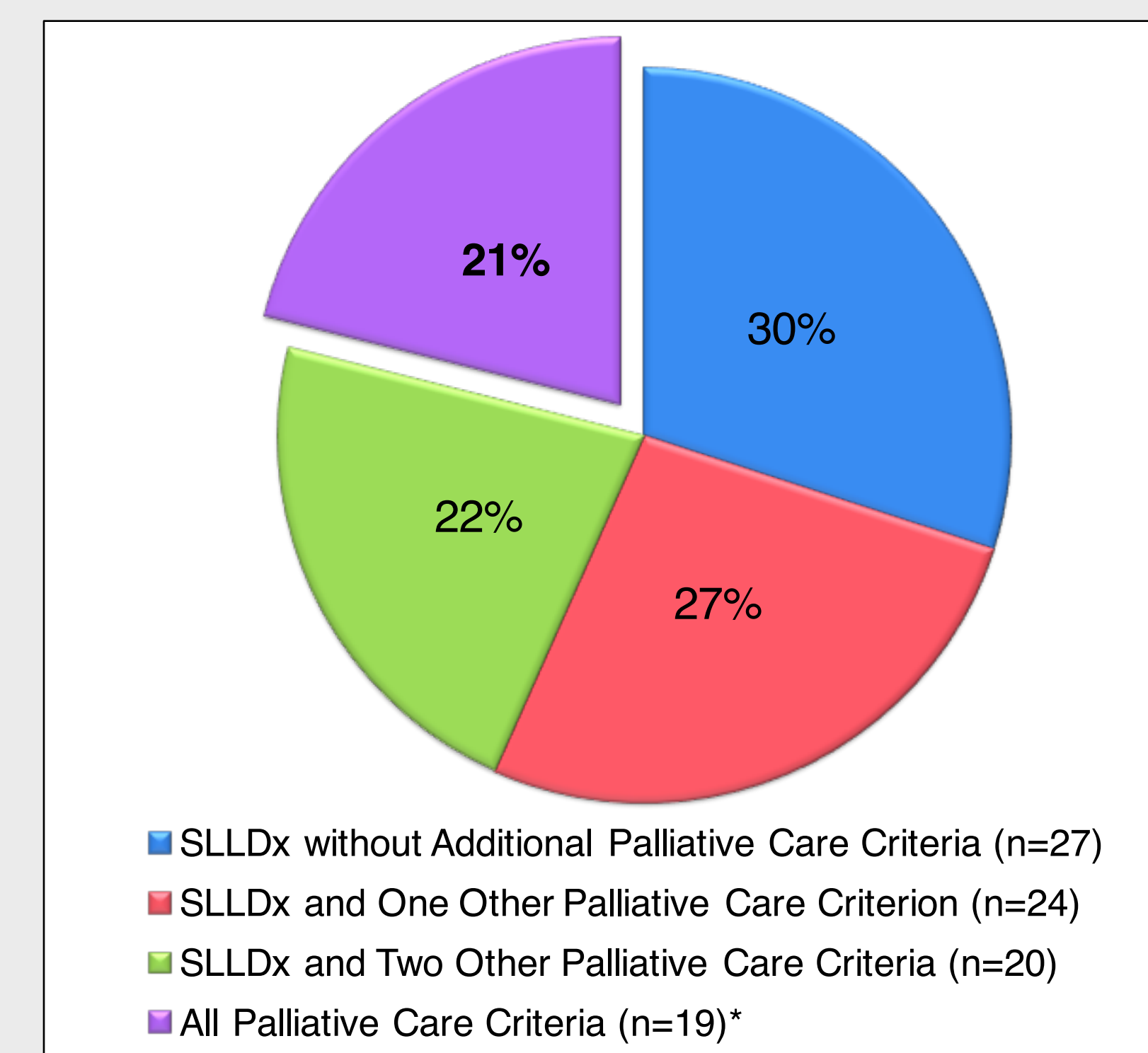
Surveys were scored as positive when any of the first four criteria were selected. Surveys were negative when the fifth (null) criteria was selected. General and subspecialty patients were combined because they were admitted to the same pediatric units. Overall, 45% of surveys screened positive.

**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%).

**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.

## 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

## Acknowledgments

Yale New Haven Children's Hospital pediatric senior residents who completed the surveys, the YNHCH resident palliative care quality improvement group for developing the screening tool criteria, and the Yale Pediatric Residency for supporting resident research.

## References

Friebert, S and Osenga, K. Pediatric Palliative Care Referral Criteria. *Center to Advance Palliative Care*. 2009

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