

Outpatient Pediatric Palliative Medicine: Complex Lives, Comprehensive Services



Rachel Vandermeer MD,* Glen Medellin MD, Jennifer Healy DO, and Sandra Sanchez-Reilly MD The University of Texas Health Science Center at San Antonio and University Health System, San Antonio, Texas

BACKGROUND

- Pediatric palliative services enroll children with life limiting, chronic illness
- Children enrolled in inpatient palliative services have a survival rate of nearly 75% at one year [1]
- Inpatient palliative services are the most prevalent service delivery model [2]
- University Health System (UHS) developed a medical home clinic that provides integrated palliative and primary care for children with medical complexity or incurable illness

OBJECTIVES

- Identify diagnoses found in an outpatient pediatric palliative care clinic (OPPPC)
- Describe technology supports used by children with medical complexity and incurable illness
- State mortality and hospice rates of children cared for in an OPPPC

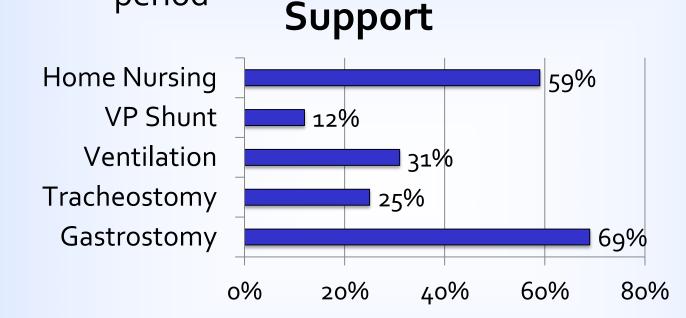
METHODS

- Retrospective chart review for patients seen at UHS OPPPC between September 2013 and February 2015
- Main Endpoints:
 - -predominant diagnoses categories
 - -technology supports
 - -community supports
 - -death rate

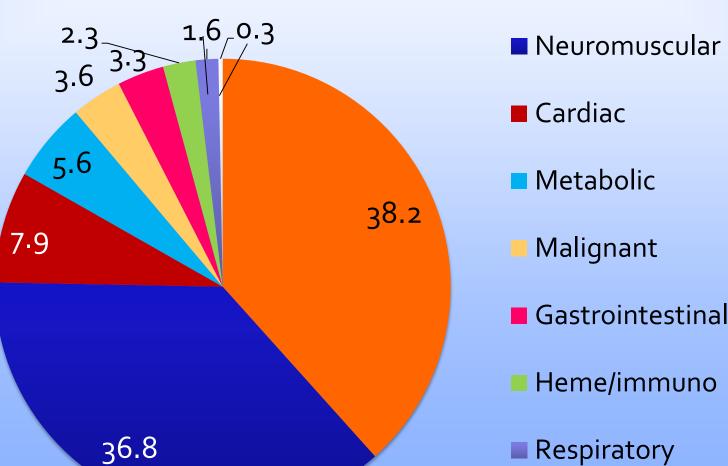


RESULTS

- 2338 visits for 359 enrolled children
- 4.3 visits per patient per year
- Death rate for clinic population is 4.3 deaths per 100 patients per year.
- ❖ 4.8% were enrolled in concurrent hospice at some point over the study period
 Current







Renal

DISCUSSION / CONCLUSIONS

- Despite life threatening illness, 95% of the UHS palliative patients do not need hospice but do need primary care
- Both primary and palliative care can be managed in a practical number of office visits
- Over half of UHS pediatric palliative patients currently benefit from home health nursing
- Care coordination for medical equipment and nursing hours is complex
- ❖ A combined primary and palliative care clinic requires embedded ancillary staff capable of addressing complex nutrition and respiratory issues
- With a death rate 100 times the typical pediatric death rate, a clinic providing care for medically fragile kids needs experts in end of life discussions and care



BIBLIOGRAPHY

[1] Feudtner, C. Pediatrics Jun 2011, 127 (6) 1094-1101; DOI: 10.1542/peds.2010-3225 [2] Feudtner, C. Pediatrics Dec 2013, 132 (6) 1063-1070; DOI: 10.1542/peds.2013-1286