Executive Summary

**Use of Palliative Care Consultation Services in Infants with Life-Threatening Conditions in a Metropolitan Hospital**

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**Introduction**

As one of 6 regional neonatal intensive care units (NICU) in Georgia, the NICU at Children’s Healthcare of Atlanta (CHOA) Hospital: Egleston manages critically ill and convalescing infants with complex and/or rare medical needs. With the assistance of over 30 specialties, the NICU team manages and provides advanced medical treatments to approximately 50 infants daily. While historic approaches to neonatology have been curative [1], palliative care has emerged as a care option for infants with life-threatening or life-limiting illness. Palliative care is a clinical approach that improves the quality of life of patients who have life-threatening conditions and their families [2] that can be used concurrently with curative measures. Palliative care is appropriate for infants born at the limits of viability, when both diagnosis and prognosis are uncertain, and in instances when prognosis alone is unclear. Using similar criteria, the majority of infants in the CHOA NICU could benefit from palliative care, however, at present, infants with life-limiting conditions at CHOA are managed on a case-by-case basis. There are no standardized guidelines for palliative care and formal consultations are handled by the Pediatric Advanced Care Team (PACT), a hospital-based interdisciplinary team introduced in 2011 to assist in the management and provision of palliative and end-of-life care.

**Methods**

The purpose of this retrospective medical record review was to describe the use of the PACT for seriously ill infants in a metropolitan hospital. The review included infants who were admitted and also died in the hospital over a two-year study time frame. Data was abstracted related to the use of palliative care consultation such as who (physician, practitioner, nurse, etc.) made the initial request for palliative care services, why a consultation was requested, age at time of consultation, and time from consultation until death. Additional data related to infant and maternal characteristics was used to describe the sample. Data was analyzed via SPSS, version 24.0, using descriptive statistics (means, frequencies, etc.) and logistic regression.

**Results**

This chart review showed similarities between infants who did and did not receive formal palliative care consultation. Logistic regression showed no significance in general characteristics of infants and mothers, including sex, race, gestational and maternal age, age at admission, age at death, or length of stay, in predicting palliative care consultation. Groups were also similar with regard to the presence of a do not resuscitate order (DNR), withdrawal of life support (WLS), and occurrence of cardiopulmonary resuscitation (CPR) in the final 48 hours of life. In evaluating invasive procedures at end-of-life, we found that infants in both groups had similar experiences with vascular access and intubation/tracheostomy attempts. Surgery, placement of interosseous access, abdominal paracentesis/drain placement, and thoracentesis/chest tube placement only occurred in infants without consultation. However infants with consultations received fewer laboratory tests and fewer transfusions of blood products.

**Discussion**

While we were unable to determine why some infants received palliative care and others did not, the findings of this chart review support the implementation of palliative initiatives in the CHOA NICU. It is my recommendation that the NICU strive to achieve three objectives:

1. **Construct Guidelines and Algorithms**- to effectively navigate palliative and end-of-life care. Examples of guidelines include order sets, pharmacologic guidelines, nursing care plans, and prompts for referral.
2. **Provide Staff Education and Training**- which are essential in the provision of palliative care [5, 6]. Education opportunities focused on palliative and end-of-life care should be offered to interdisciplinary staff providing care to infants with life-threatening or life-limiting illness [7].
3. **Provide Education for Infant Families**- in order to foster open and honest communication [8]. Beginning early in hospitalization, parents should be educated to the purpose of palliative care and options available to them.

In addition to the clinical suggestions resultant from this work, further analysis into the financial impact of palliative care is warranted. Infants who have extended stays within the NICU frequently incur charges in excess of $1M [9], a decrease in the frequency of costly medical procedures at end-of-life could have significant financial implications.

**Conclusion**

The mission of this project is “to deliver encompassing and empathetic care to infants, and families of infants, with life-limiting or life-threatening conditions.” Studies have shown that using palliative care teams and palliative initiatives (protocols, order sets, nursing care plans, staff education) increases choosing comfort care as a care-goal, decreases unnecessary medical procedures, and increases supportive services for infants and families in the NICU [3,4]. By working to standardize care and to educate staff in palliative care, the mission of this project can come to fruition.

References

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